NOTE

This Microfiche meets the quality requirements of the American National Standard for Microfiche of Documents (ANSI PH5.9-1975). However, because of imperfections in the document from which it was made, it contains images that are illegible or difficult to read. The source document for this microfiche is the best copy that could be obtained prior to filming.

Congressional Information Service, Inc.
4520 East-West Highway
Bethesda, Maryland 20814

CIS

LONG-TERM CARE AND ACCESS TO HEALTH CARE: EXAMINING THE SCOPE OF THE PROBLEMS

HEARING

BEFORE

THE PEPPER COMMISSION

U.S. BIPARTISAN COMMISSION
ON
COMPREHENSIVE HEALTH CARE

ONE HUNDRED FIRST CONGRESS
FIRST SESSION

WASHINGTON, DC

SEPTEMBER 21, 1989

PART 7

Printed for the use of the Pepper Commission

U.S. GOVERNMENT PRINTING OFFICE
26-260 ⇆ WASHINGTON : 1990

For sale by the Superintendent of Documents, Congressional Sales Office
U.S. Government Printing Office, Washington, DC 20402

J891-10

26-260 0 - 90 - 1

THE PEPPER COMMISSION

U.S. BIPARTISAN COMMISSION ON COMPREHENSIVE HEALTH CARE

JOHN D. ROCKEFELLER IV, West Virginia, *Chairman*
FORTNEY PETE STARK, California, *Vice Chairman*
MAX BAUCUS, Montana, *Vice Chairman*
DAVE DURENBERGER, Minnesota, *Vice Chairman*
BILL GRADISON, Ohio, *Vice Chairman*

MARY ROSE OAKAR, Ohio
LOUIS STOKES, Ohio
THOMAS TAUKE, Iowa
HENRY WAXMAN, California
JOHN HEINZ, Pennsylvania
EDWARD M. KENNEDY, Massachusetts
DAVID PRYOR, Arkansas

Presidential Appointees

JAMES BALOG
JOHN COGAN
JAMES DAVIS, M.D.

Staff Members

Judith Feder, *Staff Director*
Edward F. Howard, *General Counsel*

Steven C. Edelstein
Tiffany Ericksen
Robert B. Friedland
Janis E. Guerney
Monica E. McFadden
Philip Shandler
Robyn I. Stone
Dessa Vrtikapa
Judith G. Waxman
S. Mitchell Weitzman
Joy Johnson Wilson

CONTENTS

Page

OPENING STATEMENTS AND PREPARED STATEMENTS

Chairman John D. Rockefeller IV 1
Senator Dave Durenberger 6
Representative Bill Gradison 6
Commissioner James Davis 7
Representative Louis Stokes 7
Senator Max Baucus 13
Senator John Heinz 14
Senator David Pryor 15
Representative Henry Waxman 19
Representative Mary Rose Oakar 38

LIST OF WITNESSES AND OTHER MATERIAL

Pamela Young, Dickson, TN 21
Cheryl Gresek, Ipswich, MA 22
Greg Nugent, Phoenix, AZ 24
Dr. Louis W. Sullivan, Secretary, Department of Health and Human Services 40
List of members of the Advisory Council on Social Security 61
Film clip from documentary "Can't Afford to Grow Old" narrated by Walter Cronkite 63
Jim Schienle, Los Angeles, CA 65
Rebecca Schienle, Los Angeles, CA 66
Deborah Russell, Kalamazoo, MI 70
Scott Russell, Kalamazoo, MI 72
Marilyn Rubin, West Hartford, CT 74
John J. Sweeney, international president, Service Employees International Union [SEIU], AFL-CIO, CLC and chair, AFL-CIO Health Care Committee 77
Walter B. Maher, director, Federal relations for the human resources office of the Chrysler Motors Corp 91
Robert J. Blendon, Sc.D., Harvard University School of Public Health 104
Background material from Robert J. Blendon, Sc.D., Harvard University School of Public Health 108
Carroll L. Estes, Ph.D., director, Institute for Health and Aging; chairperson and professor, department of social and behavioral sciences, University of California, San Francisco, CA 124
Deborah Steelman, Chairman, Quadrennial Advisory Council on Social Security 172

APPENDIX

Prepared statements, letters, et cetera:

- Priscilla Ciccariello, chair, National Marfan Foundation, Port Washington, NY 189
- Belen B. Hickman, director, Mobility Services Inc., Atlanta, GA 200
- Joseph P. Smith, III, chairman, Public Policy Committee, Alliance of Genetics Support Groups, Washington, DC 207

LONG-TERM CARE AND ACCESS TO HEALTH CARE: EXAMINING THE SCOPE OF THE PROBLEMS

THURSDAY, SEPTEMBER 21, 1989

The Pepper Commission
U.S. Bipartisan Commission on
Comprehensive Health Care
Washington, DC.

The Commission met, pursuant to call, at 9:30 a.m., in room G–50 of the Dirksen Senate Office Building, Hon. John D. Rockefeller IV (Chairman of the Commission), presiding.

Present: Senator John D. Rockefeller IV, Senator Max Baucus, Senator Dave Durenberger, Senator John Heinz, Senator David Pryor, Representative Bill Gradison, Representative Mary Rose Oakar, Representative Louis Stokes, and Commissioner James Davis.

Also Present: Judith Feder, staff director; Edward F. Howard, general counsel; Steven C. Edelstein, Monica E. McFadden, Robert B. Friedland, Janis E. Guerney, Philip Shandler, Robyn I. Stone, Judith G. Waxman, and Joy Johnson Wilson, professional staff; Tiffany Ericksen and S. Mitchell Weitzman, staff assistants; and Jackie Shields, intern.

OPENING STATEMENT OF CHAIRMAN JOHN D. ROCKEFELLER IV

Chairman Rockefeller. The Commissioners will be coming. The Secretary will be coming shortly. We have not much time and much to do. So, the hearing will come to order.

First, I want to make an apology. If we look like some sort of vision of the Politboro up here, it's for a tactical reason. Not that we are, but that if witnesses were to be at the table directly in front of us, then they would be unavailable, so to speak, in terms of camera angles for the press. The stories that will be told this morning about those who lack health insurance and those who seek long-term health care and cannot get it are important and we want people to know about them. That is why we have this rather awkward arrangement. So, we apologize for that.

We begin today a very new phase for the U.S. Bipartisan Commission on Comprehensive Health Care and that is public hearings. We have been meeting a lot throughout the summer in closed session, listening to experts and learning and digesting and sifting and getting various points of view, but we have not really to this point opened ourselves sufficiently to public hearings and that's what we start this morning.

In fact, our public hearings, of which there will be more, will be combined with a variety of field hearings, some of which we've already had. With the background briefings that we have had throughout the summer on many occasions and the extensive consultation that's been done by our very excellent staff to our Pepper Commission, we expect to have very shortly the information and hopefully, the wisdom that we need to reach our very determined goal, which is to issue a comprehensive consensus set of recommendations on how to insure access to quality and affordable health care and long-term care for Americans of all ages.

We are known, as I indicated, as the Pepper Commission and for a very good reason, because we were and are the brainchild of Congressman Claude Pepper. He first suggested the creation of this Commission, served as its first chairman and I've got to say those are incredibly large shoes to fill. Fortunately, my colleagues on this Commission are a thoroughly distinguished lot and they are deeply committed. They bring an enormous wealth of information so that we can get toward the bold and yet workable solutions that we want really to our Nation's two most pressing health problems. That being long-term care and the problem of the uninsured and the underinsured, which that group may be close to the size of the uninsured.

So, we're going to hear this morning from not just the experts, but those who, so to speak, are victims of our so-called gold-plated system which does not reach everybody. We'll hear from some families for whom America's health care ills are not abstractions. It's not a matter of a policy debate, but crushing burdens on their daily lives. We will hear, following them, from experts who can relate those individual stories, those individual problems to the larger dimension and that is to explain how and to explain why our current system, which is so good for some, on the other hand is so completely inadequate for so many others.

When our hearings and our briefings are complete, our intention is to sit down in a rather extensive series of half-day sessions, full-day sessions, and 2-day sessions where we'll be alone, closeted away from the rest of the world, to hammer out a bipartisan, bicameral consensus on ways to attack the shortcomings in our health system. We have set the deadline of March 1, 1990.

We will lay out, incidentally, comprehensive solutions. We're going to answer the questions. We're not going to answer parts of the questions. How do we do this? How do we arrive at these solutions? What steps do we have to take to arrive at allowing people to have access to affordable health care, along with ways to pay for them. Obviously, that part is crucial. We understand particularly after the debate of the last few weeks on catastrophic health care that none of this is going to be easy, but it is our charge and it is what I, as Chairman, intend for us to do.

I might point out that it's interesting that because of the tremendous confusion in catastrophic care and, in my own personal opinion, the somewhat perilous possibilities for that being enacted into law, there's a lot of attention now and a lot of comments made in both Houses of the Congress shifting toward the Pepper Commission. We are a group who can come up with the solutions, six from the House, six from the Senate, three appointed by the administration, all far more distinguished than I and with long experience and therefore really a tremendous amount of pressure and responsibility on us, moral pressure, legislative pressure, the right kind of pressure to come up with answers.

Let me just say that everybody here wants all of this to work. We are not a frivolous group. The six from each House are people who are in a position to shepherd through the Congress legislation which, to the extent that legislation is part of our answer, we're in a position to do that. So, that lends special, I think, interest and power to this group.

In any event, we begin our process there. We have not that much time this morning and the Chairman's speech is already too long, but I will give this final observation.

Allowing these health and long-term care problems to persist not only deprives millions of Americans of what they ought to be able to have, through whatever mixture that might be suggested, it diminishes our economy. But I think in a larger sense, it diminishes the United States of America. I don't think it's possible to say finally and ultimately that we are a civilized nation when so many of our people do not have this access, do not have long-term care, do not have health insurance.

I would say also that if Claude Pepper is watching us, and I suggest that he is, his spirit is watching us, we've got a job to do and we've got to get on with it and we're going to do it.

[The prepared statement of Chairman Rockefeller follows:]

OPENING STATEMENT
by
SENATOR JOHN D. ROCKEFELLER, Chairman

at a hearing of the

PEPPER COMMISSION
(U.S. Bipartisan Commission on Comprehensive Health Care)

Thursday, September 21
Washington, DC

The hearing will come to order.

Today we begin a new phase in the work of the U.S. Bipartisan Commission on Comprehensive Health Care -- public hearings here in Washington. Coupled with our field hearings, our background briefings and the extensive consultation conducted by our staff, we hope to soon have on record the information and wisdom we need to reach our goal: to issue comprehensive, consensus recommendations on how to ensure access to quality, affordable health care and long term care for Americans of all ages.

We are now known as the Pepper Commission, in honor of the late Congressman Claude Pepper, who first suggested its creation, and served as its first chairman. Those are pretty big shoes to fill! Fortunately, my colleagues on the commission are a thoroughly distinguished lot, and deeply committed to bringing about bold, workable, solutions to our nation's two most pressing health-related problems.

We will hear this morning from some families for whom America's health care ills are not abstractions in a policy debate, but crushing burdens on their daily lives. And we will hear from experts who can relate these individual stories to the larger dimension -- and explain how our current systems for delivering care exclude large parts of our population.

When our hearings and briefings are complete, our intention is to sit down and hammer out a bipartisan, bicameral consensus on ways to attack the enormous shortcomings in health and long-term care. We have set a deadline of March 1 for issuing our reports, and we intend to meet that deadline.

We will lay out comprehensive solutions, and the steps needed to arrive at those solutions, along with ways to pay for them. We know that this will not be easy, but it is our charge, and it is what I intend for us to do.

We have, on our commission, the key leaders in Congress on the issues of health and long-term care, and three distinguished Presidential appointees. These are thoughtful men and women. They have grappled with health care issues for years, pushing for attention to the problems and offering concrete ideas for solutions. They care deeply about Americans, and believe all our citizens should have access to proper health care.

And when these good people chose me as chairman three months ago, I had this plea for them, which I now repeat -- not just for the commission members, but also for the Administration, for the advocates, and the various interested groups. That is, we must check our ideological and jurisdictional ties at the door. Let us focus on finding a common road to assure access to quality, affordable health and long-term care of Americans of all ages.

I'm going to be brief, so that we can hear from our impressive list of witnesses. But this final observation: Allowing these health and long-term care problems to persist

-- deprives tens of millions of American families of needed care or their life savings;
-- diminishes our economy and competitiveness and
-- demeans our reputation as a civilized society.

What's more, it risks the ire of Claude Pepper, whose spirit is watching us and, I hope, watching over us, seeing to it that we get the job done. Let us push on.

Chairman **Rockefeller**. Are there other opening statements from—Senator Durenberger?

OPENING STATEMENT OF SENATOR DAVE DURENBERGER

Senator **Durenberger**. Chairman, thank you very much. I'm gratified to be participating at this first public hearing in the Nation's Capital of the Pepper Commission on Comprehensive Health Care. We're here today to educate ourselves on how to achieve the full potential of an American health care system which has recently been described as a paradox of plenty and of want, a system where some receive the benefit of the most advanced medical technologies in the world, yet many poor women can't get decent prenatal care and families can't get help to keep a frail parent from having to go into a nursing home.

The formation of the Pepper Commission is an unusual and exciting coalition of primarily congressional leaders committed to rectifying serious inequities in both accessibility and financing of health benefits in this country. Unlike other commissions, this one has the power to actually act on what it finds and I trust that we will.

I apologize for the fact that coincidentally I'm cochairing the first hearing on air toxics on the clean air bill right now. So, I'm going to have to absent myself for a little while.

Thank you for this opportunity.

Chairman **Rockefeller**. Thank you, Senator Durenberger.

Congressman Gradison?

OPENING STATEMENT OF REPRESENTATIVE BILL GRADISON

Representative **Gradison**. Thank you, Mr. Chairman.

Mr. Chairman, I'm delighted that in your opening remarks you put such stress on the question of how to pay for dealing with these problems. In many ways we're victims of our own success in this country. While there are a great many who lack the protection, the means of paying for health care that they deserve, there are a great many others who have it. So, we have one of those classic situations of the haves and have-nots in the health care field.

As we in the House and Senate know with some pain, trying to figure out a way to raise the funds to pay the costs of filling these gaps at the end of the day requires convincing those who already have protection to help pay for those who do not. If recent experience is any guide, we need more help in trying to think that one through than any other single part of our charge and I mean that very seriously.

I'm extremely interested in hearing what the witnesses have to say. We had an excellent hearing in my hometown of Cincinnati and I'm sure much of the same ground will be covered here. But for this member of the Commission, in frankness, I'm a lot more interested in hearing your thoughts on how to raise the money because I think in the end that is the critical issue that has to be faced if this report is to accomplish our goals and not just gather dust on some library shelf.

Thank you, Mr. Chairman.

Chairman ROCKEFELLER. Thank you very much, Congressman Gradison.

Jim Davis?

OPENING STATEMENT OF COMMISSIONER JAMES DAVIS

Commissioner DAVIS. Thank you, Mr. Chairman.

As a physician, I would just like to say briefly, to point out how much the physicians of this country are doing to give free care to support further extension of care to the needy throughout this country.

Just yesterday I was in Kentucky simply because the medical profession is stressing service to the needy, community service and the State of Kentucky recently won our award for being the outstanding medical group who have set up their own system of providing care for those who fall through the net of Medicaid and other possible sources of help. In Louisville yesterday afternoon, I had a very memorable experience in visiting their mission house, which has been going on—they have eight different locations in the city to take care of their own people. Very stimulating day.

But what the physicians are able to do through our organizations and through our offices and through community help is not enough. So, the physicians are watching very carefully what this Commission is doing. I pledge to you that the physicians of this country will cooperate totally in trying to do everything possible to provide access to every American and to address the very trying problem of long-term care.

Thank you, sir.

Chairman ROCKEFELLER. Thank you, Jim, very, very much.

Congressman Stokes is our newest member. We're very proud of him and I believe he has some words that he wishes to say.

OPENING STATEMENT OF REPRESENTATIVE LOUIS STOKES

Representative STOKES. Thank you very much, Mr. Chairman.

Let me say at the outset, it's really a pleasure to join you and the other members of this Commission at this hearing today. As the newest member of the Pepper Commission, I'm pleased to be a part of this important body and to have the opportunity to impact upon the future health policy of our Nation.

The health issues that bring us together are of the utmost importance to the future of our citizens. The late chairman, and our good friend, Senator Claude Pepper, recognized this importance and was responsible for laying the framework for what we hope to accomplish over the next several months.

I, too, realize the gravity of our deliberations and that gravity is our inability as the wealthiest and most powerful Nation in the world, to meet the health care needs of our elderly and our inability to insure access to health care to all Americans.

I'm especially gratified to have the opportunity to bring to the attention of the Commission the viewpoint of minority Americans. These Americans face some of the greatest health challenges of all groups in our society, from infancy to old age. Our deliberations take on even further significance when we consider the fact that minority Americans are the fastest growing segment of our society.

By the year 2000, minority Americans will represent nearly 40 percent of all new workers into the American labor force. Moreover, minorities in America will comprise nearly 16 percent of all the elderly in our Nation in the year 2000, swelling to 30 percent by the year 2050.

Most importantly, I'm glad to see that the Congress is finally taking steps to bring our Nation forward to a level in sync with other developed nations in the area of health care delivery. In order to insure quality and affordable health care for all Americans, our Nation must move health care to an adequate level. We must work together with all disciplines and across all segments of our population to insure the health of each and every American in this society.

The task before us is immense. If we do not produce some meaningful solutions, we will have further jeopardized the well-being and quality of life of our citizens. Our Nation is looking to us for leadership in developing a feasible plan of action to improve access to and delivery of health care. I look forward, Mr. Chairman, to working with each of you in meeting this enormous challenge.

Thank you very much.

[The prepared statement of Representative Stokes follows:]

STATEMENT

OF THE

HONORABLE LOUIS STOKES

BEFORE THE

PEPPER COMMISSION

WASHINGTON HEARINGS

SEPTEMBER 21, 1989

I AM ESPECIALLY GRATIFIED TO HAVE THE OPPORTUNITY TO BRING TO THE ATTENTION OF THE COMMISSION THE VIEWPOINT OF MINORITY AMERICANS. THESE AMERICANS FACE SOME OF THE GREATEST HEALTH CHALLENGES OF ALL GROUPS IN OUR SOCIETY, FROM INFANCY TO OLD AGE.

OUR DELIBERATIONS TAKE ON EVEN FURTHER SIGNIFICANCE WHEN WE CONSIDER THE FACT THAT MINORITY AMERICANS ARE THE FASTEST GROWING SEGMENT OF OUR SOCIETY. BY THE YEAR 2000, MINORITY AMERICANS WILL REPRESENT NEARLY 40% OF ALL NEW WORKERS INTO THE AMERICAN LABOR FORCE. MOREOVER, MINORITIES IN AMERICA WILL COMPRISE NEARLY 16% OF ALL THE ELDERLY IN OUR NATION IN THE YEAR 2000, SWELLING TO 30% BY 2050.

MOST IMPORTANTLY, I AM GLAD TO SEE THAT THE CONGRESS IS FINALLY TAKING STEPS TO BRING OUR NATION FORWARD TO A LEVEL IN SYNC WITH OTHER DEVELOPED NATIONS IN THE AREA OF HEALTH CARE DELIVERY.

IN ORDER TO ENSURE QUALITY AND AFFORDABLE HEALTH CARE FOR ALL AMERICANS, OUR NATION MUST MOVE HEALTH CARE TO AN ADEQUATE LEVEL. WE MUST WORK TOGETHER WITH ALL DISCIPLINES AND ACROSS ALL SEGMENTS OF OUR POPULATION TO ENSURE THE HEALTH OF EACH AND EVERY AMERICAN IN OUR SOCIETY.

THE TASK BEFORE US IS IMMENSE. IF WE DO NOT PRODUCE SOME MEANINGFUL SOLUTIONS, WE WILL HAVE FURTHER JEOPARDIZED THE WELL-BEING AND QUALITY OF LIFE OF OUR CITIZENS. OUR NATION IS LOOKING TO US FOR LEADERSHIP IN DEVELOPING A FEASIBLE PLAN OF ACTION TO IMPROVE ACCESS TO AND DELIVERY OF HEALTH CARE. I LOOK FORWARD TO WORKING WITH EACH OF YOU IN MEETING THIS CHALLENGE.

THANK YOU.

MR. CHAIRMAN, FELLOW COMMISSIONERS, IT IS A PLEASURE TO JOIN YOU AT THIS HEARING TODAY. AS THE NEWEST MEMBER OF THE PEPPER COMMISSION, I AM PLEASED TO BE A PART OF THIS IMPORTANT BODY AND TO HAVE THE OPPORTUNITY TO IMPACT UPON THE FUTURE HEALTH POLICY OF OUR NATION.

THE HEALTH ISSUES THAT BRING US TOGETHER ARE OF THE UTMOST IMPORTANCE TO THE FUTURE OF OUR CITIZENS. THE LATE CHAIRMAN, AND OUR GOOD FRIEND, CLAUDE PEPPER, RECOGNIZED THIS IMPORTANCE, AND WAS RESPONSIBLE FOR LAYING THE FRAMEWORK FOR WHAT WE HOPE TO ACCOMPLISH OVER THE NEXT SEVERAL MONTHS.

I, TOO, REALIZE THE GRAVITY OF OUR DELIBERATIONS. THAT GRAVITY IS: OUR INABILITY AS THE WEALTHIEST AND MOST POWERFUL NATION IN THE WORLD TO MEET THE HEALTH CARE NEEDS OF OUR ELDERLY, AND OUR INABILITY TO ENSURE ACCESS TO HEALTH CARE TO ALL AMERICANS.

Chairman ROCKEFELLER. Thank you very much, Congressman Stokes.

Senator Baucus, do you have an opening comment?

OPENING STATEMENT OF SENATOR MAX BAUCUS

Senator BAUCUS. Yes, Mr. Chairman. Thank you very much.

Mr. Chairman, I, along with other members of the Commission, am obviously very honored to be participating in an effort which means probably more to more Americans on an individual, personal basis than any I can think of.

I had the pleasure, 9 years ago, of working with a highly respected Congressman on an issue of great importance to us that was very similar to this. That legislation was Medigap legislation which passed this Congress in 1980. Medigap insurance policies work by filling in the gaps in Medicare health coverage, the coinsurance, deductibles, and expenses above and beyond what Medicare pays for.

Back in the late 1970's there was a real problem with insurance policies that were not working with Medicare. They didn't cover enough or they covered the wrong services and the whole system was very difficult to understand. The Medigap regulations we fought for organized the chaos by requiring insurance companies to work with Medicare to fill in the gaps in order to be labeled Medigap policies. Those regulations were badly needed and they have greatly improved the insurance market.

The highly respected Congressman I worked with on Medigap passed away a few months ago, but his name lives on the work we set upon today. The Pepper Commission's charge is to fill the bigger gaps in health care, the gap of long-term care and the uninsured.

In July, I had a Pepper Commission hearing in my home State of Montana. I regret that more of my colleagues were unable to come to Montana to that hearing. I know I learned a lot and I know they would have too.

One witness, a Mr. Harry Higgins, told us about himself, his situation and his wife, June. June has Parkinson's disease. In the last 18 months, they have nearly exhausted all of their financial resources on nursing home care. Harry drives each week to a nursing home in Washington State. He leaves Montana, he crosses one State, Idaho, to go to a third State, Washington State, 5 hours each way. The nursing home costs $2,650 each month.

As we will hear today, the Higgins are not alone and there are over 30 million Americans who are without any health insurance at all. We on the Pepper Commission are looking for ways to insure that every American can have protection from the devastating costs of a long nursing home stay or an illness or a disability to fill in the gaps that our health care system all but ignores.

Today, if a person needs to go to a nursing home, the family may be forced to go broke to qualify for Medicaid. And a person without health insurance is at the mercy of providers who have to focus on the financial bottomline.

What we have now is a perverse system. It needs to be changed from a nonsystem that kicks people when they're down to an insurance program that helps people plan for their later years for themselves and for their loved ones.

Mr. Chairman, I look forward to working with you and other members of this Commission as we have a long, arduous task ahead of us, particularly in the wake of all the turmoil facing the catastrophic health insurance bill that has yet to be resolved.

Chairman ROCKEFELLER. That's for sure. Thank you, Senator Baucus.

Senator Heinz?

OPENING STATEMENT OF SENATOR JOHN HEINZ

Senator HEINZ. Mr. Chairman, first let me commend you on chairing this public hearing. Having attended so many of our working sessions with you and other members, it seems like we've had this Commission going for the more than 6 months we've been in business.

I just want to make the observation that in a very real sense, the work of this Commission is going to be very highly impacted, whether we like it or not, by decisions in the Senate Finance Committee about the Catastrophic Coverage Act. I think most of us believe that it's necessary to preserve as much of that act as possible.

We recognize that there are changes that have to be made, but that if the act is repealed, and there are many who apparently want to repeal that act, it will send a signal that Congress should not attempt to enact any legislation that benefits senior citizens, even if that legislation is aimed at the area of greatest need, long-term care.

There's a reason for that attitude: The catastrophic coverage package contains a large number of brand new and very important and highly desirable long-term care benefits. First among those, of course, is the prescription drug benefit which is the first really major long-term benefit ever written into the law. You don't have to be hospitalized with an acute illness to benefit from the prescription drug benefit. When you reach a certain threshold of financial need, you qualify.

The respite care benefit Senator Bradley and I and others have been advocating for many years is part of that legislation, although in a modified form. A slight expansion of hospice care is part of that legislation. An improvement in home health coverage is part of that legislation. An expansion of the skilled nursing home benefit is part of that legislation. If that legislation gets repealed, we will have set a precedent; namely, that we're moving backward in the health care area rather than forward.

Later today, when Senator Bentsen and the committee meet, I will be offering, perhaps with other members of the committee, some plans to save the catastrophic program. It's my hope that while there are many plans and on which any reasonable person can disagree, that we will be able to agree on one that keeps the most in the way of long-term care benefits. If we do not do that, Mr. Chairman, I feel it will deeply prejudice and profoundly undermine the work of this Commission. I would not like that to be the case.

Thank you.

Chairman ROCKEFELLER. Thank you, Senator Heinz.

Senator Pryor?

OPENING STATEMENT OF SENATOR DAVID PRYOR

Senator PRYOR. Mr. Chairman, thank you. I will not read my statement. I would like to ask unanimous consent that my full statement be placed in the record.

I would just make an observation, Mr. Chairman, that you and Senator Heinz and myself have labored hard for a long time on the Finance Committee to resolve a portion of the major issue, the long-term issue of long-term health care.

There's one thing that policymakers cannot seem to do today and that's to arrive at a solution. We can only agree on one thing, that there's a problem. How we not only arrive at that solution but also pay for that solution is seemingly the most difficult and the most painful part of a political process that we deal with at this moment.

I think there are those who are going to argue that the reaction to the Medicare Catastrophic Coverage Act is going to make the Congress and this administration far more timid, far more wary of even openly discussing the problem. This is of grave concern to me because this problem is not going to go away. Should catastrophic as we see it now be repealed, this problem is going to be with us. It is now visited upon our doorstep and we're going to have to ultimately make, I think, some very courageous decisions as to how we meet that particular challenge.

Mr. Chairman, I'd like to commend you. Throughout this debate on catastrophic, you have been one of those soldiers out there who have not only recognized the problem but are willing to bite the bullet and say: "We've got to find a solution, even though it is painful." I would like to commend you for that and I would like to commend Senator Heinz. He has been in this battle and on this battleground for a very long period of time.

So, with that, I look forward to hearing our witnesses today and trying to forge a constructive solution that will ultimately be accepted by our people.

Thank you, Mr. Chairman.

[The prepared statement of Senator Pryor follows:]

DAVID PRYOR, ARKANSAS, CHAIRMAN

JOHN GLENN, OHIO
BILL BRADLEY, NEW JERSEY
QUENTIN N. BURDICK, NORTH DAKOTA
J. BENNETT JOHNSTON, LOUISIANA
JOHN B. BREAUX, LOUISIANA
RICHARD SHELBY, ALABAMA
HARRY REID, NEVADA
BOB GRAHAM, FLORIDA
HERBERT KOHL, WISCONSIN

JOHN HEINZ, PENNSYLVANIA
WILLIAM S. COHEN, MAINE
LARRY PRESSLER, SOUTH DAKOTA
CHARLES E. GRASSLEY, IOWA
PETE WILSON, CALIFORNIA
PETE V. DOMENICI, NEW MEXICO
ALAN K. SIMPSON, WYOMING
JOHN WARNER, VIRGINIA
NANCY LANDON KASSEBAUM, KANSAS

PORTIA PORTER MITTELMAN, STAFF DIRECTOR
CHRISTOPHER C. JENNINGS, DEPUTY STAFF DIRECTOR
JEFFREY R. LEWIS, MINORITY STAFF DIRECTOR

United States Senate
SPECIAL COMMITTEE ON AGING
WASHINGTON, DC 20510-6400

OPENING STATEMENT

SENATOR DAVID PRYOR

before a hearing of

THE PEPPER COMMISSION

on

Long-Term Care and Access to Health Care:
Examining the Scope of the Problems

9:30 a.m.
September 21, 1989

SD-G50
Washington, D.C.

Good morning. I am pleased to join Chairman Rockefeller and my other colleagues on the Pepper Commission in convening the first Washington, D.C. hearing of the Commission.

All of us are here today because we are accepting the challenge of finding ways to address the major health care shortcomings this nation faces. And, with over 31 million people without any health insurance and few if any with access to affordable, comprehensive long-term care health insurance, we have quite a challenge before us.

Americans of all ages, their advocates, health care providers and insurers, the business community, and Federal, State and Local governments all have great concerns about our health care delivery system. No one is satisfied with our current hole-ridden system.

Just last month in Little Rock, I had the chance to talk with some of these dissatisfied people at a joint Pepper Commission/Aging Committee hearing I chaired on long-term care. When I called the hearing to order, we simply could not find the room to cram in all of the over 1400 people who had come to participate.

Although policymakers have a hard time finding acceptable commonground on virtually anything, there is universal agreement that we have a problem. What's more, we all agree these problems are unacceptable and must be addressed. The only consensus we are having a hard time achieving is how we address these problems and how we pay for them. And, like any other difficult problem, finding such agreement certainly will not be easy.

The Medicare Catastrophic Coverage Act is a good example of how difficult it is to reach consensus. We thought we had achieved consensus when we passed it. Obviously, we did not achieve enough of it. And, ironically, on the very same day the Pepper Commission is examining ways to provide expanded access to needed health care, the Congress is considering options to eliminate or significantly reduce some of the limited, but important long-term care benefits that the new catastrophic health law just put in place.

Without question, it is frustrating to see these benefits be threatened with extinction. I am particularly upset about the possibility of seeing one of the most important long-term care benefits, the prescription drug benefit, being targeted for elimination. However, I hope this ordeal has taught us that we must achieve broad consensus on how we address and finance the many problems that confront us. Otherwise, anything we do might be subject to the same kind of treatment the catastrophic health law is currently receiving.

Achieving such consensus will take a great deal of hard work and a willingness on everyone's part to compromise. However, in the end, it will all be worth it if we can find a way to assure access to needed health care for all Americans.

Mr. Chairman, there are those who argue that the reaction to the Medicare Catastrophic Coverage Act will make Congress and the Administration wary about tackling the difficult issues before us. While there may be some validity to that concern, I strongly believe that wariness cannot be an excuse for inaction.

The challenge before us today and facing this Commission is to make sure we do not slow down in our mission to develop a responsible, responsive and realistic proposal for meeting the health care needs of all Americans. I look forward to learning from our impressive witnesses and welcome their help in meeting this great but not insurmountable challenge.

Chairman **Rockefeller**. Thank you, Senator Pryor.

I'd also put into the record a statement by Congressman Waxman who is out of the city today and could not be here.

Just in responding to Senator Pryor's last comments, I want to reemphasize that that is often said that Congress somehow will grow more timid because of the massive reaction on the part of some against catastrophic legislation. That will not, however, intimidate or back up by 1 hour the work of this Commission. Our charge is clear. Our charge is to come up with an answer to the problem of the uninsured and the problem of long-term care in this country and we have a date by which we're meant to get it done and we are going to get it done. So, this is one group of Commissioners that is not going to be intimidated by anything that happens on that front.

[The prepared statement of Representative Waxman follows:]

OPENING REMARKS
CONGRESSMAN HENRY A. WAXMAN
CHAIRMAN
SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT
SEPTEMBER 21, 1989

America is seen throughout the world as a land of wealth and abundance. It is the place of modern medical miracles. Its health care system is unsurpassed. It is a Nation of compassion with a "safety net" of social programs to protect elderly people.

But for too many of our citizens, the America I have just described is no more than a dream. In the shadows of our great medical institutions, the poor and uninsured often forego the benefits of modern medicine. They have neither the resources to pay for care nor public or private health insurance to provide coverage. For them, routine physician visits, adequate prenatal care, and hospital services are simply beyond their reach.

And for too many older Americans, the country's "safety net" is full of holes. There is no program to protect against the high costs of nursing home services or to offer alternatives for care at home. The financial burden of providing for those who are frail and chronically ill weighs heavily on the elderly themselves and their families. The threat of losing the savings of a lifetime to pay for long-term care services has become a hard reality.

The witnesses we will hear from today will describe how illusionary the American dream is and how tattered our "safety net" has become. Their stories are ones that would shatter the world's view of our Nation.

The work of the Pepper Commission is to fashion a solution to the problems of lack of health insurance and inadequate coverage for long-term care. The task ahead requires a commitment from all Americans -- from both the public and private sectors, from both the elderly and the non-elderly, and from both Republicans and Democrats alike.

But even with such cooperation, there is no magic bullet for change. Reform won't be easy and it won't be cheap. It will require real leadership and enormous resources.

With this Commission, I believe that we have such leadership and we can find the resources. I believe, too, that we cannot and should not loose this special opportunity for progress. It is time to make the promise of America come true.

Chairman ROCKEFELLER. The Secretary has not arrived, but because we do not have much time, we're going to proceed to the witnesses. And if the Secretary should arrive, then we'll be able to hear what at least the first panel has to say.

The first panel will have to do with the problem of not having health insurance. There are three witnesses. One is Pamela Young from Dickson, TN. The second is Cheryl Gresek from Ipswich, MA, and the third is Greg Nugent from Phoenix, AZ.

To each of you, again, I would, I apologize if you can barely see us up here. It's done so that, frankly, the media can see and hear and record and react to you, which to me is much more important than anything we may have to say at this juncture.

So, Pamela Young, I welcome you and perhaps you would begin.

STATEMENT OF PAMELA YOUNG, DICKSON, TN

Mrs. YOUNG. Good morning. My name is Pamela Young. I live with my husband and four children in Dickson, TN, just outside of Nashville.

Chairman ROCKEFELLER. And I would ask, Pamela, if you would not mind, to put your face right up against the microphone. You have to sort of look at that mike as your very close friend.

Mrs. YOUNG. OK. I'm here today to share my experiences in trying to get health care for my family.

In 1981, our third child, Priscilla, was born. My husband, Tommy, was working and his job provided good insurance coverage. So even when Priscilla was born with multiple health problems, we didn't have to worry about her getting the care she required. Priscilla had to be hospitalized six times between the time she was born and 3 years of age. The doctors finally determined that she had a twisted hip and duplicate urinary tract, conditions which required surgery.

Between the insurance and aid from Crippled Children's, we were well covered through all of these hospitalizations and everything went smoothly.

This couldn't have been more of a contrast to what we would experience 2 years later with our fourth child. Our daughter, Mary, developed an abscess in her kidney from blockage. Tommy had been laid off and we no longer had any insurance. Mary had to be hospitalized and we knew that there was no way we could afford to pay the bill on our own. We had no choice. Tommy moved out of our house and in with his sister, I filed for a trial separation so that the children and I would be eligible for Medicaid. That Medicaid card got us the care Mary needed, which included 9 weeks in 2 hospitals. When her condition improved, 3 months later, Tommy moved back in.

It seemed wrong to have the Government foot that bill, but it was the only way we could think of to assure that Mary would get the care she needed to make her well.

A year ago, we got another frightening reminder of what it's like to try to get urgently needed health care without insurance. Last September, our son, Jonathan, developed abscesses on each side of his body, just above the pelvic bone, from badly infected insect bites. They were large and oozing, so I rushed him to the emergency room of the Vanderbilt University Hospital. The nurse took one look at him and told me that he needed surgery and would have to be admitted as an inpatient. But when they found out that we had no insurance, they didn't want to take him, even though I assured them that both my husband and I were working and that we would pay off the bill, whatever it was.

I persisted and refused to leave and finally they agreed to let a doctor see him. Instead of surgery, they gave my son two shots of morphine, cut him open right there in the emergency room. Believe me, it was difficult to sit there and listen to my son scream in pain. They packed his wounds and sent us home and told me to bring Jonathan back in a day or so to have the dressings changed.

When we came back it was the same story all over again. Because we didn't have any insurance, they didn't want to treat Jonathan. So, I took Jonathan and started driving to other area hospitals and pediatricians. None of them wanted to touch him because Vanderbilt had started the treatment. I even took him to a public clinic for the homeless. I was beside myself. I was about to drive 400 miles to my home in Muncie, IN, in the hopes that out of mercy a pediatrician we knew there would see him, when an attorney I was put in contact with through the public clinic called and said he had arranged for us to go to Vanderbilt Hospital. They denied they had ever treated Jonathan, but they agreed to take him.

Jonathan is fine now, but we ran up $4,000 to $5,000 at Vanderbilt Hospital. We still owe money to Vanderbilt, but we pay as we can. We have to screen our phone calls to avoid harassment by the hospital's bill collectors. We don't own anything of value because the hospital would just take possession. We live in an old farmhouse and drive a 1973 Chevy Impala. I used to have a management position, but I took a job for $4 an hour stocking shelves at the local K-Mart. It was about half of what I used to make, but K-Mart provides health insurance for me and my family. After our experiences, we could no longer risk living without insurance.

The whole incident with Jonathan was very frightening for us, but it seems to me that you shouldn't need a lawyer to get the health care you need.

Chairman **Rockefeller**. Pamela Young, thank you very, very much.

I know the Secretary has arrived.

Mr. Secretary, you're a very busy man and I need to know quite honestly whether or not you need to proceed right away or whether you can sit through these three panel cases.

Secretary **Sullivan**. I can come after this panel.

Chairman **Rockefeller**. You're very kind. Thank you very much, sir.

Then I would call on Cheryl Gresek.

STATEMENT OF CHERYL GRESEK, IPSWICH, MA

Mrs. **Gresek**. Yes. I'm Cheryl Gresek and I'm from Massachusetts.

I gave birth, 2 years and 10 months ago, to my sixth child, Daniel. Daniel was born with a very rare heart defect. I thought I was a sensitive person and could understand how parents felt when they had a child born with a defect, but I didn't understand one-tenth until Daniel was born.

He was on a warming table because he could no longer regulate his body temperature. He had an incision from the base of his neck to his bellybutton. They had to break the bone to perform open heart surgery, a bone which will never heal. His head was shaved on both sides so they could attach IV lines. He was hooked to a heart monitor and had a feeding tube down one nostril and a respirator tube down the other.

They had to cut into his wrists and ankles, behind his knees and inside his elbows and into his groin to reach veins they could use. For 7 weeks, I couldn't hold him, feed him, or change him. All I could touch were the tops of his hands and his cheeks.

When you have a child born with a defect like this, it rips your whole world apart. Everything revolves around this child and his medical needs. There is an enormous amount of stress. We felt at the time that we were lucky to have health insurance. My husband and his brother own a small business. They have a group policy which covers us as well as their employees. We knew that Daniel's bills would be high, but we felt that we would be covered.

But after our insurance company started getting Daniel's medical bills, our premium increased from $198 a month to $766 a month. I called them, thinking their computer had made an error. I was told that they were not in the business of paying our medical bills. They were there to defer the cost. My brother-in-law's insurance premium went up as did our employees. We were forced to make many changes in order to keep our business open. My husband and brother-in-law took a cut in pay. We had to drop our employees off of our policy, promising them that when we resolved this problem we would again offer them insurance.

This was hard for us to do because we had always offered insurance and felt strongly that our employees should have this protection. We put our townhouse on the market. We paid the premium increase plus the $1,100 a year deductible. We knew we could not afford to pay for Daniel's medical needs. Daniel's bills for the first 3 months were $150,000. This is the bill that we received. The total amount for the first 2 years was over $300,000.

For 6 months, we tried to talk to the insurance company, hoping to resolve this problem. All they would tell us was that they were well within their rights to increase our premium. We couldn't believe this, so we hired a lawyer to review our case. He wrote them a letter. They wrote back that they were fully justified in increasing our premium. They did not violate the Massachusetts consumer protection statute or the Fair Debt Collection Practice Act. If we did not like what they were doing, we could discontinue our participation in their group plan and purchase insurance from another carrier.

I felt they were laughing at us. They knew, as we did, that with Daniel's preexisting condition, no other company would insure us.

We contacted the insurance commissioner's office. After investigating, they said that there was nothing they could do. They said that the Hartford Insurance Co. was trying to force us to drop their insurance by raising our rates until we could no longer afford it.

They said Hartford could charge us more a month than what my husband makes in a month.

After 13 months of paying $766 a month, our premium was then increased to $1,375 a month. My brother-in-law, as a single, was increased to $500 a month. We knew there was no ceiling on how high they could raise our rates. We knew also that we could not pay Daniel's medical expenses without losing everything.

It was an agonizing decision when we decided to drop our policy. What amazes me is that we hear so much about getting the uninsured insured and here we are, willing and able to pay a reasonable amount for insurance and we're forced off. Our only fault is having had a sick child.

After many months of looking and calling anyone we could think of, we found Common Health. We pay $58 a month for Daniel's insurance and $250 for us with a private insurance. I'm happy to say our employees are now covered. As relieved and happy as we are to have Common Health, we are still very angry at the Hartford Insurance Co. At a time we should have been totally concentrating on Daniel and our family, we had to put so much time and effort into our insurance problems. They put us through hell.

A few months ago, I happened to see a commercial for the Hartford Insurance. Maybe you've seen it. It's the one with the deer running free in the woods. I'm not sure what the analogy is, but their new slogan is: "When you need us the most, that is when we are at our best." They have proven to me that what they are best at is getting high risk people off their insurance policies.

My husband and I have always paid for health insurance, since we were 18 years old and off of our parents' policies. But when we needed them the most, they left us high and dry. There are a lot of people out there that fall through the cracks. There is no Common Health for them, like Patty Burns waiting for a kidney transplant. Her insurance went up to $1,200 a month. Or Neil Ferguson, a builder; he has cancer. He had a bone marrow transplant and he is now in remission. He has to pay $2,000 a month for himself and three employees.

After living and dealing with this problem for almost 3 years and listening to others with similar insurance problems, I'm convinced we need more than Band-Aid solutions. We need a total revamp of the insurance company policy or a national health plan. It seems the only thing private insurance companies insure is their profits. Insurance is not a luxury. It is a necessity.

Thank you.

Chairman ROCKEFELLER. Cheryl, thank you very, very much.

I would now call on Greg Nugent.

STATEMENT OF GREG NUGENT, PHOENIX, AZ

Mr. NUGENT. Good morning, Mr. Chairman and members.

My name is Greg Nugent. I'm from Phoenix, AZ. This is an emotional subject for me, so excuse me.

Chairman ROCKEFELLER. You take your time, Greg.

Mr. NUGENT. In 1986, a boy of mine, 3½ years old, came down with a serious or severe tumor in his head. It was malignant. He was considered not to live and we proceeded with care at a private facility in Phoenix. Having not been insured at the time, shortly after admitting my boy to this hospital, after extensive treatments deemed necessary, the bills were mounting. I happened to be, at that time, an unemployed self-employed subcontractor in the State of Arizona with no insurance.

Of course, I was not denied treatment. However, I was certainly indebted to the hospital, of which today I am being sued for.

My boy is alive today, thank God. But I believe that the health care provided to him was provided only because of the diligent work of my wife and myself to provide the best care possible because of the system in the State of Arizona.

As you members probably know, the State of Arizona does not have Medicaid. There is a pilot program that is regulated by the State of Arizona for which there are guidelines for eligibility. We, as a family, earned approximately $15,000 in 1985. That, of course, disqualified us for the eligibility for what is known as the Arizona Health Care Cost Containment System. Because of our ineligibility, my son was to be moved to an inadequate facility because this private facility felt that they would not be receiving their due and fair costs for the treatment my boy was receiving.

We fought the system because the facility they wanted to move my boy to did not have the proper staffing, nor the equipment to provide the treatment of radiation. They told me that they would put my boy in an ambulance daily and transfer him to the radiation facility to provide this treatment, which to me was asinine.

My boy received extensive treatments. He was hospitalized for months. Didn't eat for 4 months. Was home on health care. It cost in excess of $100,000. Finally, after I was so indebted to the hospital and through the diligent efforts of my wife and myself of fighting the system, we did become eligible for the Access Program in the State of Arizona, which is similar, I understand, to Medicaid. Workers at the hospital advised me that now, because I no longer have any assets left, because I hadn't worked and because the debts were so high that the Access system would begin to pick up the medical costs. However, there were still problems. Once my son was released from the hospital, and which we're thankful for, he still continues to need treatment, of which we cannot receive unless we provide the funding ourselves. He, because of the tumor, received severe damage to his pituitary gland of which he will not grow. We have to artificially inject him daily for possibly 10 years at the cost of $15,000 to $18,000 a year, of which I have no money for. I am broke. I lost the house. I nearly lost the family and I'm tired of it.

If this Commission can do one thing, it would be my request to provide information to our leaders: "Let's take care of our most important commodity, the people of America and not treat them like dogs."

My boy today is still, as I say, treated like a dog and it's not fair. I've paid taxes all my life. It's just not fair.

I thank you.

[The prepared statement of Greg Nugent follows:]

AMERICAN CANCER SOCIETY

TESTIMONY OF

GREG NUGENT

PHOENIX, ARIZONA

BEFORE THE PEPPER COMMISSION

SEPTEMBER 21, 1989

For further information, please contact:
John H. Madigan, Jr. or Kerrie B. Wilson
American Cancer Society
316 Pennsylvania Avenue, SE
Suite 200
Washington, DC 20003
(202) 546-4011

Good morning, Mr. Chairman and members of the Commission. My name is Greg Nugent and I am from Phoenix, Arizona. In August of 1986 my world almost came to an end, my son Ryan who was 3 years old, was diagnosed with a malignant tumor in his head. For those of you familiar with medical terminology, it was a stage three tumor or paramengial. Doctors gave us very little hope. My wife Linda and I began an odyssey into a hellish world of hospitals and treatments just to keep our little boy alive. To most people this would be hard to endure. Yet imagine being told that your son may not live to see his 4th birthday and " by the way Mr. Nugent we see that you have no health insurance so we cannot provide Ryan with the medical treatment he needs at this hospital."

At the time Ryan was first diagnosed, I was an unemployed subcontractor. I was a tile setter by trade, and my work depended on what construction was going on at any one time. My wife was working as a waitress earning $2.01 an hour, plus tips. Our annual income after taxes was about $12,000; we had a good life. Besides Ryan, we have three other children, Tiffany, now 20, another son Travis, now 17, and a daughter Jessica, now 11. We owned our own home, and we managed to pay our mortgage of $750.00 and make sure the kids had decent clothing and healthy food. Like a lot of Americans we were able to stay one step ahead of the bill collectors and provide our kids with a wholesome family life. Unfortunately, health insurance was not on the list of affordable items; we thought food and shelter were the most important things for our family. My wife, my kids and myself were young and healthy.

My wife's employer did not offer health insurance coverage, and being self-employed it was extremely expensive to purchase a policy for my family. When we thought about buying it, we looked at our situation and realized we just could not swing it. We were not on welfare, we were not begging in the streets, we paid our fair share of taxes. Linda and I have the same dreams for our kids and our futures as other parents do, we just could not afford health insurance. Then disaster struck, and our little boy was dying before our eyes.

Ryan was first diagnosed in late August of 1986. We had taken him to Phoenix Children's Hospital. Within 24 hours of being admitted, he was being aggressively treated for a tumor behind his nose and sinuses. His situation was so precarious that he was being given radiation and chemotherapy at the same time. Normally a patient will receive one or the other, or have one follow the other. Ryan was near death and the doctors decided to pull out all the stops. By this time my wife Linda quit her job to be with Ryan 24 hours a day. By the second week of September the medical bills were around $35,000 and mounting; they eventually exceeded $100,000 for the period when he was diagnosed and was in the hospital receiving treatment. Ryan was in the hospital for two months.

Immediately after Ryan was hospitalized, we were called down to the finance office of the hospital and told that since we had no health insurance we had to apply for assistance from the state. In Arizona, its called Arizona Health Care Cost Containment System (AHCCS), and is the equivalent to Medicaid in other states. They reviewed our situation and told us that we did not qualify for the program because our income was too high and we owned a home. In reality, Linda was not working, I was in between jobs so there was really no money coming in during that time. Linda applied for food stamps so we could feed our other children, and they told her that Ryan would qualify for Supplemental Security Income (SSI) from the federal government, and if we got SSI money than we would automatically become eligible for AHCCCS. It took a month to get the paperwork done, and the bills went unpaid.

We finally received notice that we qualified for AHCCCS, and we began receiving SSI checks for approximately $300 a month. At that time, we were told that Ryan would have to be moved to the County hospital. We learned that the County Hospital could not provide Ryan with the radiation treatment he desperately needed. When we pointed this out to them, they said that they would send him by ambulance each day to and from the county hospital to the Children's Hospital to give him radiation. At this point I exploded. Mr. Chairman, my three year old son was dying, he could not eat, and the bureaucracy says they have to move him to a hospital that can't help him, and then send him back and forth between hospitals to get treatment. Our doctors told us that it was important that Ryan remain where he was. By that time we were at the mercy of the bureaucracy. My wife Linda went to meet with the President of the hospital and tearfully begged him to allow Ryan to stay and be treated at the Phoenix Children's hospital. He listened carefully and had us speak to another person and we eventually won agreement that Ryan could stay and be treated at the Phoenix Children's Hospital. We know now that the way AHCCCS works, we could only get treatment at certain hospitals in the county. However, we also learned that investigators from the state had been overheard to say that Ryan's case was hopeless and it would be far cheaper to treat him at the county hospital to save money. Some non-medical bureaucrat had decided that my son wasn't going to live and that he wasn't worth the money.

Today, Ryan is six years old. He has just started first grade. He is like every other six year old, eager to get out of bed in the morning, to go play with friends, eat pizza and trade baseball cards. Linda and I realize that Ryan will have a lot of problems in the future. He will never see out of his left eye, his teeth are falling out, and he seems to get the flu or a cold a little easier than most kids. Some of the other kids don't understand what he's been through and they make fun of the way he looks --

just another problem we have to deal with. But, Mr. Chairman, he is alive and we still have hope!

We eventually lost our home. My wife and I have gone through a terrible situation that nearly destroyed our marriage. My family and I now live in a two bedroom apartment, three kids in one bedroom and Linda and I in the other. Our two cars are over ten years old. We are being sued for over $7000 in unpaid medical bills. Linda went back to work as a waitress; she makes $2.75 an hour, plus tips. I have found a job doing maintenance work for a catering company which pays about $5.00 an hour, but I'm looking for a better job. This year, we think our annual income this year will be about $15,000. It may not seem like much, but my family and I will survive. We are not on welfare, we're paying taxes, and most importantly, Ryan is alive.

But what does our future hold? As I said earlier, Ryan received very aggressive treatment for his cancer. This resulted in side effects that have stunted his growth. He is now taking a growth hormone medication that costs about $15,000 a year. He also takes medication to control his thyroid. He is blind in one eye, and will need surgery to correct the facial deformities. He faces major dental problems. We tried to get some dental work done under AHCCCS, but they have only one dentist in the area who will see AHCCCS patients, and they are can't handle the patient load. Linda did some research and found a dental group that charges us only $15 per visit to help families in our situation. This makes us feel good, to have some control over the care our son is getting. Besides all the things I just mentioned, he needs regular medical checkups to make sure that everything is okay. Linda takes him to Children's Rehabilitative Services for treatment and every three months they give us the medication for him. Quite frankly, we are afraid to ask who is paying the bill. When Linda went back to work, we were notified that the SSI payments would stop and so we don't know our status with the state.

The company that Linda is with now offers a health insurance plan. It would cost $50 a month, just to cover Linda; it would take her entire paycheck for the month to cover the whole family, excluding Ryan of course. Our rent payment is $340 a month, plus utilities which have been as high as $180 a month. We're back where we started. After paying the rent, buying food, and clothing our children, we have little if anything left over. We now know that health insurance is very important, but how are we going to pay for it?

Mr. Chairman, I appreciate the opportunity to testify before your commission today. When I first told my story in June at an American Cancer Society hearing in Phoenix on health care problems for the poor, I saw for the first time how many Americans are facing the same problems that my family has had. The people here today have told you similar stories. I know now there are 37 million Americans without health insurance. I hope that the Pepper Commission can come up with some solutions to the problems I faced: how to make health insurance affordable to all Americans, and how to improve AHCCCS, and programs like it, to meet the needs of cancer patients like Ryan Nugent. Thank you.

Chairman **Rockefeller**. Thank you, Greg, very, very much.

I want to say at the beginning that I respect each of you for going through this. In other words, you're trying to reach out to help other people by doing something which is painful for you and that is to share your problems with the country so that things will get better and I respect you for that and thank you for being willing to help us and a lot of other people in that way.

Pamela, maybe I'd just ask you a question, if that's all right. You're now in a job in which you have insurance coverage.

Mrs. **Young**. Yes.

Chairman **Rockefeller**. Let's suppose somebody were to come along and offer you a job that paid a lot more money, but did not bring with it health insurance. Would you take the job or not?

Mrs. **Young**. No; I would not. I've already had that offer and have turned it down.

Chairman **Rockefeller**. And again, can you explain a little bit your sense and your motivation for your decision?

Mrs. **Young**. You have to have health insurance or you can't get care. That's all there is to it. You just cannot get it. You walk into a hospital and the first thing they say is: "Do you have insurance?" When you stand there and tell them no, they say: "Well, I'm sorry. You have to give us some kind of a payment now or we're not going to see you." If you don't have any cash on you, you're just out of luck, no matter how sick you are, no matter how sick your child is, unless you stand there and just get really ugly with them and fight and fight and fight until they'll see you just to shut your mouth.

Chairman **Rockefeller**. You had, in every sense, exhausted every effort to try to find insurance in some way? You have the insurance through your job now. That's the only way that you can see to holding insurance?

Mrs. **Young**. That's the only way we can afford to hold insurance. When you have four children, insurance is just outrageous for a family of six. That's the only way we can afford to have insurance. I could make a lot more money than $4 an hour.

Chairman **Rockefeller**. And in a sense that's what America is about, isn't it? I mean, in other words, if you're able to improve your condition and you're able to make more income, that's what the deal is meant to be. But what you're saying is the health insurance really comes before the income because you have parental responsibilities and you just have to do the $4 an hour because it brings with it health insurance.

Mrs. **Young**. That's correct.

Chairman **Rockefeller**. Let me ask a question, if I might, of Cheryl.

The bills total $300,000, I guess that's what you——

Mrs. **Gresek**. This is only a bill for $150,000. I didn't bring all the bills with me.

Chairman **Rockefeller**. Yes. Well, there's another $150,000, I think you left it at home.

Mrs. **Gresek**. Yes. That's not all that you pay, you know. When you have somebody that is sick, it cost us $600 just to park our car to go in and see our child the first 3 months that he was in the hospital. So, a family goes through more than just paying for the medical expenses. There are other things that they have to pay for that medical insurance just wouldn't cover anyway.

Chairman ROCKEFELLER. Did you look around for any other insurance coverage when your own company, your own carrier raised, as you described, the insurance premium so rapidly and to such an enormous amount? If you did, did you find that the results were virtually the same?

Mrs. GRESEK. They wouldn't take us—they wouldn't cover Daniel. We couldn't get other insurance because of his now preexisting condition.

Chairman ROCKEFELLER. By which you mean the problem that's being faced now: More and more carriers are eliminating those who have so-called preexisting conditions and they simply say: "We're not interested."

Mrs. GRESEK. Right. I'll tell you, when we got Daniel on Common Health and then we went out and applied for insurance, it took us 5 months to get on insurance. I know how people feel who are uninsured because for 5 months we were totally uninsured. Every time they put my husband's name into the computer, my son's records would come up. Out of the nine people that we employed, the insurance company sent a nurse out only to my husband to have his heart checked, his blood pressure, and his heart rate checked.

We had asked them, because in Massachusetts you can either get full coverage on Common Health or you can get what they call a wraparound. You can have your son insured under your policy for everything but the preexisting condition and then Common Health would take care of the preexisting condition. They didn't even want to talk to us about that. They did not want to have anything to do with my son. They didn't even want to insure him for any—what would happen to "a normal child."

Chairman ROCKEFELLER. Greg, can you describe for me, or any of you, try to get across, even as you have been doing so, what this does to concentration on the job, what it does to a family, what it does to your ability to be parents and to give attention to your other children, et cetera. If any of you could just speak on that. To not be able to pay the bills, to not be able to get health insurance, to not be able to get medical care because you don't have health insurance, what happens to the nuclear family?

Mrs. GRESEK. Even when we had health insurance, you have to pay your premium on time, but they don't have to pay the bills on time. We used to get many letters from collection agencies, phone calls. My husband was very nervous of what it would do to our business. We've always had a good credit rating. But this is something that tears you completely apart. It's something that you wake up with in the morning, you think about all day long, and you go to bed with it at night.

Chairman ROCKEFELLER. Greg, you had to get rid of everything you had, am I right, to try to qualify for Arizona's plan? The State limit was what, $4,000 per year? Then, in a sense, you came in at about $6,000 a year, so that even after that you still couldn't qualify. You were too rich to qualify and too poor to do anything about your health problems for your children.

Mr. **Nugent**. That's correct. There's a margin there apparently that we fit into that would make us ineligible. To this day, we are ineligible. It's only because both my wife and I work. However, we do not make very much money. My wife is a waitress who earns $2.01 an hour, plus gratuity. I work as a caterer presently because I gave my business up, for $5 an hour. Consequently, there's not much wages there.

There are problems with the system that I truly can't answer why, but we just do not fit into the mold. Like I say, my son needs quite a bit of care today yet. But in order for us to receive that care, we have to foot the expenses or we have to find some, excuse the expression, handout from somebody or some agency that is willing to assist us.

Chairman **Rockefeller**. Are there questions from Commission members?

Senator **Pryor**. Could I ask one question of each?

Chairman **Rockefeller**. Of course.

Senator **Pryor**. Mr. Nugent and Mrs. Young, let me just say, by the way, to all of you, and Mrs. Gresek, your testimony was not only eloquent, it was very, very moving and we appreciate it.

Mrs. Young, you testified that the bill collectors are after you. Is this correct? Have they actually entered a judgment against you of any kind or has it gone that far?

Mrs. **Young**. That's correct. They haven't entered a judgment against me yet. They call my workplace and they call me at home all the time, constantly.

Senator **Pryor**. And with regard to the debt, Mr. Nugent, what is your situation with your past debt? Are you being sued or hounded or what?

Mr. **Nugent**. That's correct. I'm being sued. I was delivered a subpoena about 6 weeks ago. What's going to take place from this point on, I don't know. I have nothing no more, so I don't know what they could do.

Senator **Pryor**. And Mrs. Gresek, you have $300,000 in bills. What is your situation with regard to the attempt to collect that sum?

Mrs. **Gresek**. The insurance company has paid the $300,000. They just kept going up and up on our premium. So, right now, we're doing fine. But I'll tell you, it is a tremendously stressful situation to deal with—insurance companies seem to attack the most vulnerable part of our society, our sick. I don't think that that's right.

Senator **Pryor**. Thank you very much.

Thank you, Mr. Chairman.

Chairman **Rockefeller**. I want to acknowledge the presence of Congresswoman Mary Rose Oakar. We're delighted to have you, Mary Rose.

Are there anymore questions? There are many questions, I guarantee you and I hope you'll be staying throughout the hearing. I thank you enormously. You are part of a process which is putting bricks on bricks that's going to lead to something and you've made an enormously valuable contribution, as well as showing, I think—you know, caring for your children and a tremendous amount of courage to be here and I thank you all very, very much.

Representative **Oakar**. Senator, could I just ask unanimous consent?

Chairman **Rockefeller**. Yes, please.

Representative **Oakar**. I'd like to ask unanimous consent that an opening statement that I had prepared be part of the record. Thank you, Senator.

Chairman **Rockefeller**. Absolutely.

[The prepared statement of Representative Oakar follows:]

REMARKS OF
THE HONORABLE MARY ROSE OAKAR
September 21, 1989

MR. CHAIRMAN:

THANK YOU FOR THE OPPORTUNITY TO ADDRESS THIS HEARING. I ALSO WANT TO THANK YOU FOR HOLDING THIS HEARING AND COMMEND YOUR ABLE STAFF FOR ASSEMBLING THIS IMPRESSIVE LIST OF WITNESSES. I AM CONVINCED THAT PUBLIC HEARINGS, SUCH AS OUR DISCUSSION TODAY, PROVIDE IMPORTANT INFORMATION ABOUT THE GREAT HEALTH CARE ISSUES WE FACE. AGAIN, I APPLAUD YOUR EFFORTS TO HOLD THIS HEARING.

AS YOU KNOW, MR. CHAIRMAN, I HAVE A DEEP AND LONG-STANDING INTEREST IN THE ISSUES WE WILL DISCUSS TODAY. I HAVE BEEN CONCERNED WITH HEALTH CARE PROBLEMS AND THE EFFECTS THEY HAVE ON ALL AMERICANS EVER SINCE I FIRST CAME TO CONGRESS. IN FACT, I HAVE INTRODUCED DOZENS OF BILLS OVER THE YEARS DEALING WITH EVERYTHING FROM BREAST CANCER SCREENING, TO PROVIDING LONG-TERM CARE, TO CREATING A UNIVERSAL HEALTH CARE SYSTEM FOR THE ELDERLY. I AM GRATEFUL FOR THE OPPORTUNITY TO SERVE ON THIS COMMISSION AND WORK TO RESOLVE THESE PROBLEMS ONCE AND FOR ALL.

MR. CHAIRMAN, THE PEPPER COMMISSION IS CHARGED WITH FINDING SOLUTIONS TO THE ENORMOUS AND DAMAGING HEALTH CARE PROBLEMS FACING OUR NATION; NAMELY, CREATING ACCESS TO COMPREHENSIVE HEALTH CARE SERVICES FOR ALL AMERICANS, AND PROVIDING COMPREHENSIVE LONG-TERM CARE FOR THE ELDERLY AND DISABLED. I BELIEVE THAT THE MOST IMPORTANT WORD IN BOTH OF THESE MANDATES IS

THE WORD "COMPREHENSIVE". IT SUCCINCTLY DESCRIBES THE BEST METHOD OF RESOLVING BOTH OF THESE PROBLEMS AND IT FORMS THE BASIS OF MY WORK IN THE HEALTH CARE AREA.

AS WE ARE CURRENTLY WITNESSING WITH THE EMOTIONAL DEBATE SURROUNDING THE CATASTROPHIC HEALTH CARE BILL, OUR CITIZENS WANT AND NEED **COMPREHENSIVE** HEALTH CARE SERVICES. AT THE TIME WE WERE WORKING ON THE CATASTROPHIC BILL, THE DECISION WAS MADE NOT TO INCLUDE LONG-TERM CARE SERVICES. WE IN CONGRESS HAVE DISCOVERED THAT AMONG OUR CONSTITUENTS, MOST SENIORS INCLUDE LONG-TERM CARE COSTS AMONG THE MOST CATASTROPHIC OF ALL HEALTH CARE EXPENSES. YET, THE CONGRESS CHOSE NOT TO OFFER THESE SERVICES IN THE CATASTROPHIC BILL'S PACKAGE OF BENEFITS. I FIRMLY BELIEVE WE SHOULD USE THIS ELEMENT OF THE DEBATE OVER THE CATASTROPHIC BILL AS A GUIDE FOR PROVIDING THE COMPREHENSIVE SOLUTION MANDATED IN THE LANGUAGE THAT CREATED THIS COMMISSION.

MR. CHAIRMAN, IN CLOSING, I WANT TO IMPRESS UPON OUR AUDIENCE HOW STRONGLY I SUPPORT THE WORK OF THE PEPPER COMMISSION. THE COMMISSION IS THE BEST OPPORTUNITY WE HAVE EVER HAD TO FIND A LASTING SOLUTION TO THE ENORMOUS HEALTH CARE PROBLEMS FACING AMERICA. THE PROBLEM IS SO LARGE THAT IT HAS ENTERED THE REALM OF INTERNATIONAL ECONOMIC COMPETITIVENESS AND TRADE ISSUES. WE MUST FIND A COMPREHENSIVE SOLUTION TO HEALTH CARE PROBLEMS IN ORDER TO CONTINUE OUR STATUS AS THE GREATEST NATION IN THE WORLD.

THANK YOU.

Chairman ROCKEFELLER. I'm very pleased now to be able to call Dr. Louis Sullivan, who is the Secretary of Health and Human Services.

Mr. Secretary, we're very grateful that you have taken the time to be with us. That's important to us because as we, on the Pepper Commission, do our work, we want to be doing it together with the administration in a bipartisan, as I indicated in my opening remarks, bicameral fashion. Therefore, your presence symbolically is important to us and your words are going to be very important to us.

We welcome you, sir.

STATEMENT OF DR. LOUIS W. SULLIVAN, SECRETARY, DEPARTMENT OF HEALTH AND HUMAN SERVICES [HHS]

Secretary SULLIVAN. Thank you very much, Mr. Chairman and members of the Commission.

I am certainly pleased and honored to be here with you today to testify before this Commission at the first of several hearings you are having here in Washington.

You've been asked to address what many people consider to be the two most pressing issues facing our health care system: providing long-term care for the chronically impaired, and insuring access to basic health care for the estimated 31 million Americans who lack health insurance. Certainly you have heard already some of the deficiencies in our system from the prior witnesses.

Today, I'd like to give my perspective on what some of the problems are with our current policies and programs. However, my principal reason for coming here today is to share with you my pledge to bring all the resources of my Department to bear in seeking compassionate, effective, and affordable solutions to these complex issues. It is my great hope that together we can achieve the spirit of cooperation, the sensitivity, and the wisdom needed to build a better health care system for all Americans.

In keeping with this pledge, in June I appointed the Advisory Committee on Social Security. A key part of my charge to the Council members was that they develop recommendations for more stable health care financing for the aged, the disabled, the poor, and the uninsured. You will be hearing shortly today from Ms. Deborah Steelman who chairs this Council.

I also want to announce to you that I have instructed the Under Secretary of my Department to forward to me recommendations for my consideration for the reform of our health care and long-term care financing policies. The recommendations are to be submitted to me no later than October 1990. I've asked that the following issues be addressed:

First, fundamental, long-term reform of public and private health care financing to improve access to care of the poor, minorities, the uninsured, and other population groups.

Two, improvements in the performance of our current Medicaid Program to make it more equitable, more attractive to potential providers, while at the same time improving quality and controlling costs.

Three, creating a partnership between Federal, State, and local governments and the private sector to strengthen the health care delivery system and make it more responsive to the needs of the poor.

Finally, increasing the participation of the private sector in long-term care financing, improving access to home- and community-based services, and strengthening the quality of long-term care.

I hope that I'll have frequent opportunities to return and discuss these issues with you.

Now, let me briefly review some of my thinking with respect to the uninsured.

First, I believe it is important to personalize and put a face on the uninsured population. An uninsured person may be a child in a low-income family or a poor pregnant woman, a homeless person or a childless adult with a physical or mental disability. He or she may be part of the working corps whose employer does not offer insurance and may not be able to afford private coverage.

Many uninsured people live below the poverty level, and yet as you've already heard earlier today, do not meet the Medicaid eligibility requirements in their State.

In short, the uninsured include people of many backgrounds. Friends and neighbors, people from all walks of life who have one thing in common, they are not included in a health care system that the rest of us often take for granted.

In addition to the obvious risks faced by the uninsured if they are unable to obtain basic health services, their exclusion from the traditional health care system contributes to a number of other serious problems, such as too much primary care is delivered in hospital emergency rooms and other inappropriate settings.

Second, delivery of health services to the uninsured puts a disproportionate burden on our public hospitals and clinics.

Third, the need to deliver acute care makes fewer resources available for services to maintain a chronic condition, to treat a minor health problem, or provide preventive services to our population. The result is that minor problems then become serious ones which in the end require even more medical resources. Further health care resources in underserved areas become even more scarce because of the absence of insurance.

Last, health facilities are forced to subsidize unpaid services by increasing the cost to insured patients or asking local taxpayers to further finance indigent care.

Increasing the availability of health insurance that is affordable, that assures access to needed care, and that controls costs has been and remains one of President Bush's first priorities. Within weeks of taking office, the President proposed a major expansion of the Medicaid Program to provide greater access to care for pregnant women and infants.

Let us now turn to the issue of long-term care for the elderly. I'd like to discuss a broad approach to long-term care financing rather than specific policy options. In this arena, I think it is extremely important that we agree on what the problems are before we attempt to solve them and that we invest only in solutions that are likely to yield measurable results.

Medicare and Medicaid now provide access and funding for nursing home care. As a result, most older Americans who cannot afford to pay for institutional care do not go without. But obviously, improvements can be made here. The impetus for long-term care reform is based on a belief that the elderly who need long-term care, especially nursing home residents, are being forced to bear an excessive share of the cost. Long-term care for the chronically ill and disabled is said to be the major uncovered catastrophic, out-of-pocket health care cost facing the elderly. This is because Medicare, for the most part, does not cover extended nursing home stays or home- and community-based services, and private long-term care insurance is still in an early stage of development.

The Medicaid Program, the main source of public financing for long-term care, requires persons whose income and assets are above eligibility levels to apply these resources to the cost of their care before they can qualify for assistance. Critics of these rules believe that they are demeaning and force people to use up their life savings before the Government will help.

There's no doubt that Medicaid long-term care policies need to be reexamined. To the extent that they contribute to unreasonable economic burdens on people who need long-term care, they should be changed. However, until recently it has been difficult to understand very much about the out-of-pocket burden on nursing home residents in relation to their ability to pay.

A recently completed HHS study found that the percentage of nursing home residents who never go on Medicaid is much higher than previously known. Moreover, most Medicaid recipients did not enter as private pay patients or exhaust their life savings and then become eligible. The majority of Medicaid recipients became eligible immediately upon nursing home admission and made their financial contributions to the cost of care from monthly Social Security and pension income.

My point is that we cannot devise workable solutions for excessively burdensome out-of-pocket costs until we define what these are. We must decide how much we should ask people to contribute to the cost of their care, particularly people whose wealth would otherwise permit them to pay for most of their care out-of-pocket. We must further address an important philosophical issue that all of us in society must deal with. That is, the extent to which public long-term care policy should support the understandable and natural desires of older people to pass on some of their wealth to their children.

In closing, I want to emphasize that I do think there are very real problems with our current long-term care policies and programs. To achieve this goal, it is my intention to do the following:

One, devise policies and programs to strengthen the private long-term insurance market and make sure that people get good value for their money.

Two, achieve a better balance in funding between home- and community-based care and nursing home care.

Finally, to insure that Federal and State requirements for obtaining long-term care financing assistance do not result in unfair and unreasonable economic burdens on people who need long-term care and cannot afford to pay for it.

Now, I intend to work hard on this agenda during my time at the Department of Health and Human Services. I thank you for the opportunity to appear before you today. I'd be pleased to respond to any questions that you may have.

[The prepared statement of Secretary Sullivan follows:]

TESTIMONY OF

LOUIS W. SULLIVAN, M.D.
SECRETARY
DEPARTMENT OF HEALTH AND HUMAN SERVICES

BEFORE THE

UNITED STATES BIPARTISAN COMMISSION ON
COMPREHENSIVE HEALTH CARE
(THE PEPPER COMMISSION)

SEPTEMBER 21, 1989

MR. CHAIRMAN AND MEMBERS OF THE COMMITTEE, I AM PLEASED AND HONORED TO BE HERE TODAY TO TESTIFY BEFORE THE PEPPER COMMISSION AT THE FIRST OF SEVERAL HEARINGS IN WASHINGTON. YOU HAVE BEEN ASKED TO ADDRESS WHAT MANY PEOPLE CONSIDER TO BE THE TWO MOST PRESSING ISSUES FACING OUR HEALTH CARE SYSTEM -- PROVIDING LONG-TERM CARE FOR THE CHRONICALLY IMPAIRED AND ENSURING ACCESS TO BASIC HEALTH CARE FOR THE ESTIMATED 31 MILLION AMERICANS WHO LACK HEALTH INSURANCE.

TODAY, I WOULD LIKE TO GIVE MY PERSPECTIVE ON WHAT SOME OF THE PROBLEMS ARE WITH OUR CURRENT POLICIES AND PROGRAMS AND SOME OF THE FACTORS THAT SHOULD BE CONSIDERED IN THE WEIGHING OF ALTERNATIVE SOLUTIONS. HOWEVER, MY PRINCIPAL REASON FOR COMING HERE TODAY IS TO SHARE WITH YOU MY PLEDGE TO BRING ALL THE RESOURCES OF MY DEPARTMENT TO BEAR IN SEEKING COMPASSIONATE, EFFECTIVE AND AFFORDABLE SOLUTIONS TO THESE COMPLEX ISSUES. IT IS MY GREAT HOPE THAT TOGETHER, WE CAN ACHIEVE THE SPIRIT OF COOPERATION, THE SENSITIVITY AND THE WISDOM NEEDED TO BUILD A BETTER HEALTH CARE SYSTEM FOR ALL AMERICANS.

IN KEEPING WITH THIS PLEDGE, IN JUNE, I APPOINTED THE ADVISORY COUNCIL ON SOCIAL SECURITY; A KEY PART OF MY CHARGE TO THE COUNCIL MEMBERS WAS THAT THEY DEVELOP "RECOMMENDATIONS FOR MORE STABLE HEALTH CARE FINCANCING FOR THE AGED, THE DISABLED, THE

POOR, AND THE UNINSURED." YOU WILL BE HEARING SHORTLY FROM DEBORAH STEELMAN, WHO CHAIRS THIS COUNCIL.

I ALSO WANT TO ANNOUNCE TO YOU THAT I HAVE INSTRUCTED THE UNDER SECRETARY OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES TO FORWARD TO ME RECOMMENDATIONS FOR MY CONSIDERATION FOR REFORM OF OUR HEALTH AND LONG-TERM CARE FINANCING POLICIES. THE RECOMMENDATIONS ARE TO BE SUBMITTED TO ME NO LATER THAN OCTOBER OF 1990. I HAVE ASKED THAT THE FOLLOWING ISSUES BE ADDRESSED:

- WHAT FUNDAMENTAL, LONG-TERM REFORMS OF PUBLIC AND PRIVATE HEALTH CARE FINANCING ARE NECESSARY TO IMPROVE ACCESS TO CARE OF THE POOR, MINORITIES, THE UNINSURED AND OTHER POPULATION GROUPS WHO ARE DISADVANTAGED BY CURRENT POLICIES AND PROGRAMS?

- WHAT CAN WE DO RIGHT NOW TO IMPROVE THE PERFORMANCE OF THE CURRENT MEDICAID PROGRAM TO MAKE IT MORE EQUITABLE, MORE ATTRACTIVE TO POTENTIAL PROVIDERS, WHILE AT THE SAME TIME IMPROVING QUALITY AND CONTROLLING COSTS?

- HOW CAN WE CREATE A PARTNERSHIP BETWEEN FEDERAL, STATE AND LOCAL GOVERNMENTS AND THE PRIVATE SECTOR TO STRENGTHEN THE HEALTH CARE DELIVERY SYSTEM AND MAKE IT MORE RESPONSIVE TO THE NEEDS OF THE POOR? FINALLY,

- WHAT SHOULD WE DO TO INCREASE THE PARTICIPATION OF THE PRIVATE SECTOR IN LONG-TERM CARE FINANCING, IMPROVE ACCESS TO HOME AND COMMUNITY-BASED SERVICES AND STRENGTHEN QUALITY OF LONG-TERM CARE.

I HOPE THAT I WILL HAVE FREQUENT OPPORTUNITIES TO RETURN AND DISCUSS THESE ISSUES WITH YOU.

NOW LET ME BRIEFLY REVIEW SOME OF MY THINKING WITH RESPECT TO THE UNINSURED. FIRST, I BELIEVE IT IS IMPORTANT TO PERSONALIZE AND "PUT A FACE" ON THE UNINSURED POPULATION. AN UNINSURED PERSON MAY BE A CHILD IN A LOW INCOME FAMILY, A POOR PREGNANT WOMAN, A HOMELESS PERSON, OR A CHILDLESS ADULT WITH A PHYSICAL OR MENTAL DISABILITY. HE OR SHE MAY BE PART OF THE "WORKING POOR" WHOSE EMPLOYER DOES NOT OFFER INSURANCE, AND MAY NOT BE ABLE TO AFFORD PRIVATE COVERAGE. MANY UNINSURED PEOPLE LIVE BELOW THE POVERTY LEVEL AND YET DO NOT MEET MEDICAID ELIGIBILITY REQUIREMENTS IN THEIR STATE. IN SHORT, THE UNINSURED INCLUDE PEOPLE OF MANY BACKGROUNDS -- FRIENDS AND NEIGHBORS, PEOPLE FROM "ALL WALKS OF LIFE" WHO HAVE ONE THING IN COMMON: THEY ARE NOT INCLUDED IN A HEALTH CARE SYSTEM THAT THE REST OF US OFTEN TAKE FOR GRANTED.

IN ADDITION TO THE OBVIOUS RISK FACED BY THE UNINSURED IF THEY ARE UNABLE TO OBTAIN BASIC HEALTH SERVICES, THEIR EXCLUSION FROM THE TRADITIONAL HEALTH CARE SYSTEM CONTRIBUTES TO A NUMBER OF OTHER SERIOUS PROBLEMS:

- TOO MUCH PRIMARY CARE IS DELIVERED IN HOSPITAL EMERGENCY ROOMS AND OTHER INAPPROPRIATE SETTINGS; THE RESULT IS FRAGMENTATION OF CARE, INCOMPLETE CARE AND EXCESS COST;

- DELIVERY OF HEALTH SERVICES TO THE UNINSURED PUTS A DISPROPORTIONATE BURDEN ON PUBLIC HOSPITALS AND CLINICS; THIS THREATENS QUALITY OF CARE AND THE VERY EXISTENCE OF PUBLIC FACILITIES;

- IN ALL FACILITIES, THE NEED TO DELIVER ACUTE CARE MAKES FEWER RESOURCES AVAILABLE FOR SERVICES TO MAINTAIN A CHRONIC CONDITION, TREAT A MINOR HEALTH PROBLEM, OR PROVIDE PREVENTIVE SERVICES. THE RESULT IS THAT MINOR PROBLEMS BECOME SERIOUS PROBLEMS WHICH IN THE END, REQUIRE MORE MEDICAL RESOURCES AT GREATER COST;

- FURTHER, HEALTH CARE RESOURCES IN UNDERSERVED AREAS BECOME EVEN MORE SCARCE BECAUSE OF THE ABSENCE OF INSURANCE. CONSEQUENTLY, THE WORKING CONDITIONS OF HEALTH CARE PROVIDERS BECOME EVEN LESS ATTRACTIVE AND MANY ARE NO LONGER WILLING TO WORK IN THESE AREAS;

- LAST, IN ORDER TO SURVIVE, HEALTH FACILITIES ARE FORCED TO SUBSIDIZE UNPAID SERVICES BY INCREASING THE COSTS TO

INSURED PATIENTS OR ASKING LOCAL TAXPAYERS TO FURTHER FINANCE INDIGENT CARE; IN THIS WAY, THE COST OF HEALTH CARE IS DRIVEN HIGHER FOR EVERYONE.

INCREASING THE AVAILABILITY OF HEALTH INSURANCE THAT IS AFFORDABLE, THAT ASSURES ACCESS TO NEEDED CARE, AND THAT CONTROLS COSTS, HAS BEEN AND REMAINS ONE OF PRESIDENT BUSH'S FIRST PRIORITIES. WE HAVE ALREADY MADE A BEGINNING. WITHIN WEEKS OF TAKING OFFICE, THE PRESIDENT PROPOSED A MAJOR EXPANSION OF THE MEDICAID PROGRAM TO PROVIDE GREATER ACCESS TO CARE FOR PREGNANT WOMEN AND INFANTS. OTHER ASPECTS OF THIS INFANT MORTALITY INITIATIVE WILL INCREASE OUTREACH THROUGH EXISTING CHANNELS AND PROGRAMS TO PROMOTE EARLY ENTRY INTO PRENATAL CARE AND EXPAND CASE MANAGEMENT AND REFERRAL ACTIVITIES.

LET US NOW TURN TO THE ISSUE OF LONG-TERM CARE FOR THE ELDERLY. I WOULD LIKE TO DISCUSS A BROAD APPROACH TO LONG-TERM CARE FINANCING RATHER THAN SPECIFIC POLICY OPTIONS: IN THIS ARENA I THINK IT IS EXTREMELY IMPORTANT BOTH THAT WE AGREE ON WHAT THE PROBLEMS ARE BEFORE WE ATTEMPT TO SOLVE THEM AND THAT WE INVEST ONLY IN SOLUTIONS THAT ARE LIKELY TO YIELD MEASURABLE RESULTS.

MEDICARE AND MEDICAID NOW PROVIDE ACCESS AND FUNDING FOR NURSING HOME CARE. AS A RESULT, MOST OLDER AMERICANS WHO CANNOT AFFORD TO PAY FOR INSTITUTIONAL CARE DO NOT GO WITHOUT. BUT OBVIOUSLY IMPROVEMENTS CAN BE MADE HERE.

THE IMPETUS FOR LONG-TERM CARE REFORM IS BASED ON A BELIEF THAT THE ELDERLY WHO NEED LONG-TERM CARE, ESPECIALLY NURSING HOME RESIDENTS, ARE BEING FORCED TO BEAR AN EXCESSIVE SHARE OF THE COSTS. LONG TERM CARE FOR THE CHRONICALLY ILL AND DISABLED IS SAID TO BE THE MAJOR UNCOVERED "CATASTROPHIC" OUT-OF-POCKET HEALTH COST FACING THE ELDERLY. THIS IS BECAUSE MEDICARE, FOR THE MOST PART, DOES NOT COVER EXTENDED NURSING HOME STAYS OR HOME AND COMMUNITY-BASED SERVICES AND PRIVATE LONG-TERM CARE INSURANCE IS STILL IN AN EARLY STAGE OF DEVELOPMENT.

THE MEDICAID PROGRAM, THE MAIN SOURCE OF PUBLIC FINANCING FOR LONG-TERM CARE, REQUIRES PERSONS WHOSE INCOME AND ASSETS ARE ABOVE ELIGIBILITY LEVELS TO APPLY THESE RESOURCES TO THE COST OF THEIR CARE BEFORE THEY CAN QUALIFY FOR ASSISTANCE. CRITICS OF THESE RULES BELIEVE THEY ARE DEMEANING AND FORCE PEOPLE TO USE UP THEIR LIFE SAVINGS BEFORE THE GOVERNMENT WILL HELP.

THERE IS NO DOUBT THAT MEDICAID LONG-TERM CARE POLICIES NEED TO BE REEXAMINED. TO THE EXTENT THEY CONTRIBUTE TO UNREASONABLE ECONOMIC BURDENS ON PEOPLE WHO NEED LONG TERM CARE, THEY SHOULD BE CHANGED. HOWEVER, UNTIL RECENTLY IT HAS BEEN DIFFICULT TO UNDERSTAND VERY MUCH ABOUT THE ACTUAL OUT-OF-POCKET BURDEN OF NURSING HOME RESIDENTS IN RELATION TO THEIR ABILITY TO PAY.

A RECENTLY COMPLETED HHS STUDY FOUND THAT THE PERCENTAGE OF NURSING HOME RESIDENTS WHO NEVER GO ON MEDICAID IS MUCH HIGHER THAN PREVIOUSLY KNOWN. MOREOVER, MOST MEDICAID RECIPIENTS DID NOT ENTER AS PRIVATE PAY PATIENTS, EXHAUST THEIR LIFE SAVINGS, AND THEN BECOME ELIGIBLE. THE MAJORITY OF MEDICAID RECIPIENTS BECAME ELIGIBLE IMMEDIATELY UPON NURSING HOME ADMISSION AND MADE THEIR FINANCIAL CONTRIBUTIONS TO THE COST OF CARE FROM MONTHLY SOCIAL SECURITY AND PENSION INCOME.

MY POINT IS THAT WE CANNOT DEVISE WORKABLE SOLUTIONS FOR EXCESSIVELY BURDENSOME OUT-OF-POCKET COSTS UNTIL WE DEFINE WHAT THESE ARE. WE MUST DECIDE HOW MUCH WE SHOULD ASK PEOPLE TO CONTRIBUTE TO THE COST OF THEIR CARE, PARTICULARLY PEOPLE WHOSE WEALTH WOULD OTHERWISE PERMIT THEM TO PAY FOR MOST OF THEIR CARE OUT OF POCKET. WE MUST FURTHER ADDRESS AN IMPORTANT PHILOSOPHICAL ISSUE THAT ALL OF US IN SOCIETY MUST DEAL WITH -- THE EXTENT TO WHICH PUBLIC LONG TERM CARE POLICY SHOULD SUPPORT THE UNDERSTANDABLE AND NATURAL DESIRES OF OLDER PEOPLE TO PASS ON SOME OF THEIR WEALTH TO THEIR CHILDREN.

IN CLOSING, I WANT TO EMPHASIZE THAT I DO THINK THERE ARE VERY REAL PROBLEMS WITH OUR CURRENT LONG-TERM CARE POLICIES AND PROGRAMS. MOREOVER, THE DEMAND FOR LONG-TERM CARE IS LIKELY TO DOUBLE OVER THE NEXT 30 YEARS. THE QUESTION WE FACE IS HOW TO

PAY FOR THE CARE OF MANY MILLIONS OF PEOPLE WHO WILL NO LONGER BE ABLE TO MANAGE FOR THEMSELVES OR WITH THE HELP OF THEIR FAMILIES. FEDERAL AND STATE GOVERNMENT ALREADY PAY FOR 1/2 OF THE NATION'S NURSING HOME BILL. THIS STRONG PUBLIC ROLE MUST CONTINUE.

TO ACHIEVE THIS GOAL IT IS MY INTENTION TO:

- DEVISE POLICIES AND PROGRAMS TO STRENGTHEN THE PRIVATE LONG-TERM INSURANCE MARKET SO MANY MORE PEOPLE CAN AFFORD TO BUY INSURANCE AND I WANT TO MAKE SURE THAT PEOPLE GET GOOD VALUE FOR THEIR MONEY.

- TO ACHIEVE A BETTER BALANCE IN FUNDING BETWEEN HOME AND COMMUNITY-BASED CARE AND NURSING HOME CARE.
  I THINK THIS IS WHAT PEOPLE WANT, I THINK IT IS RIGHT...THE QUESTION IS HOW TO MAKE IT AFFORDABLE AND OF GOOD QUALITY.

- FINALLY, TO ENSURE THAT FEDERAL AND STATE REQUIREMENTS FOR OBTAINING LONG-TERM CARE FINANCING ASSISTANCE DO NOT RESULT IN UNFAIR AND UNREASONABLE ECONOMIC BURDENS ON PEOPLE WHO NEED LONG-TERM CARE AND CANNOT AFFORD TO PAY FOR IT.

I INTEND TO WORK HARD ON THIS AGENDA DURING MY TIME AT THE DEPARTMENT.

THANK YOU FOR THE OPPORTUNITY TO APPEAR BEFORE YOU TODAY. I WOULD NOW BE HAPPY TO ANSWER ANY QUESTIONS YOU MAY HAVE.

Chairman ROCKEFELLER. Thank you very much, Mr. Secretary. We appreciate very much your taking the time to come before us.

We are looking, are we not, at a problem of simply staggering proportions? Is it not fair to say that we're looking essentially at some 30 million to 37 million Americans who do not have insurance, more than 30 million seniors with little or no protection or prospects, so to speak, for long-term care? Really this kind of an unprecedented problem has suddenly come up on this Nation, and is beginning to grab the Nation's attention and our national budget and corporate budgets, and it has the real possibility of simply overwhelming us unless we can come to grips with it.

Secretary SULLIVAN. Yes.

Chairman ROCKEFELLER. Do you agree with the almost—not only the staggering proportions of the problem that we're talking about here, but the frightening possibilities in terms of the human cost if we don't solve them and yet the overwhelming consequences that they're going to have on public and private institutions no matter which way we try to solve them?

Secretary SULLIVAN. Yes, Mr. Chairman, I would agree with you that this is indeed a major problem facing us as a society and one that demands our urgent attention. I'm certainly very pleased that this Commission, among others, is indeed looking at this problem.

I would comment further that many of those 31 to 37 million uninsured Americans are individuals who have jobs. These are not simply the unemployed individuals. But the costs of the insurance for these individuals is such that they cannot afford it on the incomes that they have. So this is certainly a very significant problem that we look forward to working with you and the Steelman Commission and the members of my Department in trying to find solutions.

I believe that we not only can find solutions, we must find solutions. The nature of our society is one where we have always believed in providing the best opportunities for health care for our citizens because the fundamental basis of our strong society is having a healthy population. So it is a very significant problem.

Chairman ROCKEFELLER. One more question from me and then I will go on to others.

The polls, such as they are, have indicated that overwhelmingly Americans are dissatisfied with our health care system or are frightened about their prospects within that health care system. On the one hand, we have the gold-plated system where there's incredible emphasis on technology, 50 percent of the cost of health care for the average American taking place, let's say, within the last few months of that American's life. And yet on the other hand, we have so many people who can't get health care.

How do we get here?

Secretary SULLIVAN. Well, I think that it's a very complex question as to the various factors that led to where we are now. But I certainly would agree that the status quo is not acceptable, that we have to find ways to address these problems so that people like the witnesses who just preceded me, who represent I'm sure many other citizens around the country, don't have to focus all of their energies in trying to access the health care system. What they experience is not a user-friendly system. We need to change that because that certainly is not the kind of system that we want in our society.

I would also say that for those individuals who have the resources, I would agree with you that American medicine at its best has no equal. We have many individuals coming from all over the world here for training or for highly specialized care that is often not available elsewhere. So, clearly, we have the technological capability. What we really are facing is changing the system to indeed address those gaps, those very significant gaps that exist that affect all too large a number of our citizens. And as you have already heard, many times they are in a position where they are demeaned through circumstances that are clearly not their fault. Where we have honest, hardworking, productive Americans who have a misfortune and where the safety net, that is supposed to be there through private insurance and through other systems, doesn't work, we need to indeed focus on those gaps.

Chairman ROCKEFELLER. And to create that safety net through one way or another and to close those gaps through one means or another. You would agree?

Secretary SULLIVAN. Yes; I agree fully.

Chairman ROCKEFELLER. Congressman Gradison?

Representative GRADISON. Thank you, Mr. Chairman.

Thank you, Mr. Secretary. It was an excellent statement.

I want to share with you my sense of the urgency of these issues and indicate to you the charge which we're faced with and ask your help in our meeting our deadlines. Congress has asked us to make our recommendations by March 1 of next year. Now, that date wasn't accidental. That was to give the Congress an opportunity next year to receive our recommendations and look them over and, if some or all of them make sense, to legislate on them next year.

I have no idea what our recommendations will be, but if history is any guide they probably will create a framework for action, a series of steps to be taken over a period of time. If that be the case, if we're eventually going to have a comprehensive system, we have to get on with it and get started.

I'd mention this, Mr. Secretary, because, in frankness, I am disappointed by the timetable of your own internal recommendations. As I understand your statement, your Under Secretary has been directed to come up with recommendations by October. I don't see why it should take so long. We've got to get up to speed. We're not experts in this, but you are and your Department is. That's the repository for the expertise in the executive branch for dealing with these issues. It would be my very serious hope and recommendation to you that you change the date from October to March so that your folks can come up with recommendations about the same time we do and we can then have something to lay before the Congress.

My concern very simply is that we're going to be first out of the box. Based on my experience serving in the executive branch, the likely response to the executive branch will be: "Well, that's all very interesting, what came out of the Pepper Commission, but our internal studies aren't finished until October and therefore we don't want to comment yet on what you've come up with up there." What that really means in terms of the cycle under which we operate is that nothing would happen, nothing at all in 1990 and then we get cranked up again as a new Congress in 1991, which is always a slow process.

Senator **Pryor**. Can I just interrupt and just say amen and hallelujah to what you've said, Congressman Gradison?

Representative **Gradison**. I'm just trying to get us working on the same timetable, that's all.

The second thing I'd like to mention, and again this is gratuitous, but we're legislators and you're an administrator. I don't think an administration recommendation on this subject coming out of your Department alone gives us what we need. I think we need something comparable or integrated into your study from the Treasury because, frankly, I think the heart of this thing is how to raise the money. I think the rest of it is pretty much just conversation. We know what the needs are and I think we've got to kind of figure out how much we can raise and then figure out what that will buy. It probably won't buy everything we'd like.

So, it would just again be my suggestion that you go back and have another talk with your Under Secretary about how to get the financing of this thing built into your study.

I'd welcome your comments, but I did want to lay this upon you because it's an excellent opportunity for me to do so.

Secretary **Sullivan**. Thank you very much, Mr. Gradison. Let me point out that my statement said no later than October, because indeed we do share with you and the Members of the Congress a sense of urgency here. I'm sure that some of our work will be completed before October, but the full array of issues that I've asked my Department to address may very well realistically take that period to be completed. But certainly, we will do everything that we can to have that timetable as short as possible because we are committed to addressing this problem in a meaningful way.

Representative **Gradison**. Thank you, Mr. Secretary.

Chairman **Rockefeller**. Jim Davis?

Commissioner **Davis**. Good morning, Dr. Sullivan, and I use your senior title rather than call you Mr. Secretary.

Let me tell you again how happy the physicians of the country are that you are heading up Health and Human Services. We have full confidence that you are going to make a real difference in health care there and we thank you for accepting that responsibility.

I commend you on appointing the Advisory Committee on Social Security, but I have exactly the same concerns that Representative Gradison does about the timetable of it. As an example, just the question of access. I think it is very commendable that you in the administration have recommended changes in Medicaid to help pregnant women and infants, but aren't there other ways in which we can improve Medicaid access long before next fall hopefully? I would encourage your Department to take some very serious looks at what can be done to improve access. If it's going to take that long, well into 1990, for the Steelman Council to report out, I would be very hopeful that your Department would lead us in helping access by improving other aspects of Medicaid almost immediately, if that's possible, sir.

Secretary **Sullivan**. Thank you very much, Dr. Davis, and we certainly appreciate your statements of support. Indeed, I want to assure you and the other members of the Commission, and our citizens in general, that we are giving this a full effort. As we do come up with solutions, we're going to be coming forward with them. So, we do not intend for a period of silence to occur between now and October 1990, but the full array of issues that I've asked the Department to work on and address, might take that period of time. But I think it's fair for us to go back and see if even the date for completion of everything might be moved up.

Commissioner **Davis**. Thank you, sir.

Chairman **Rockefeller**. Congressman Stokes?

Senator Pryor?

Senator **Pryor**. Louis, please go right ahead.

Representative **Stokes**. I yield to the Senator.

Chairman **Rockefeller**. Senator, go ahead.

Senator **Pryor**. Well, I must say I probably should wait a few more minutes before I say anything because my temperature is a little bit high right now, Dr. Sullivan.

I once again thank you for being here. I admire you, I respect you. If I had one word of admonition this morning it is please don't become a victim of your own bureaucracy at HHS.

Let me say why I say that. When Congressman Gradison so eloquently stated: "I hope that you could hurry on this study," he was expressing our collective frustration. Last year, if it's not my mistake, your Department spent something like $31 million to private consulting firms to do studies. Somewhere in that stack of $31 million worth of consulting fees that they paid to consulting firms and the beltway bandits, there's enough evidence, enough statistics for you to make recommendations to coincide with our recommendations where you're not dragging along 6 and 8 months late.

This can be done and I beg you, sir, I beg you to do this. We cannot continue sitting around here, as you have said and as we say, looking at the problem. We've got to find some solutions. I'm trying to put myself right now in the shoes of these three wonderful, brave people that have come before this Commission this morning. And really, I kind of hate to tell you, I'm afraid they're going to go away and they're going to say: "Well, it's just more bureaucratic talk." We can't continue to do that. This problem is so acute, so severe.

Mr. Chairman, Dr. Davis and I had a hearing in Little Rock last month, in Arkansas. We had 1,400 people who came to see what we were going to do about this problem. These were not lobbyists, they were not influence peddlers, they were not bureaucrats, they were people, they were people who were afraid, who had no insurance, no coverage, who are going to go through the same thing that these witnesses that we're hearing today.

Yet we seem to just say: "Well, we're going to look at the problem." This Commission and your Department, sir, are going to have to stop looking at the problem. We're going to have to look at a solution because we're beyond the problem-looking stage. We're beyond the problem of developing statistics. We've just got to do it.

All I'm saying to you, you're a breath of fresh air in this city. Don't become victimized by your own bureaucracy and don't let them, sir, please, tell you that you can't make this recommendation by March, along with this Commission. We've got to walk lockstep together in this problem if we are going to find that solution.

Thank you very much, sir. Thank you.

Chairman ROCKEFELLER. Congressman Stokes?

Representative STOKES. Thank you very much, Mr. Chairman.

Mr. Secretary, I appreciate your appearance here this morning and the testimony you've given this Commission. As we listen to each one on this Commission, it's apparent that we're talking about a national problem, one of enormous gravity and concern, not only to this Commission but to all Americans.

I'm just concerned in this respect. You bring to your position as Secretary of HHS an enormous background, not only as a distinguished physician, as one who has been a founder of and president of a medical school, training physicians and now the important position you occupy. I'm just wondering, considering the gravity of this problem, have you really tapped into all of the national resources available to you to come up with what Senator Pryor has just talked about in terms of solutions? You've spoken in your testimony about the need for solutions. It seems that perhaps this problem is of such gravity that you need to expand beyond your own Department. You need to tap the best minds in the country, the top physicians in the country, the top medical care professionals in the country, in order to come up with the kind of solutions we need to address a national problem.

I'm just wondering if we are, in fact, doing that.

Secretary SULLIVAN. Thank you very much, Mr. Stokes. Indeed, you are quite correct that we need to have input from all of these segments of our society and I have had and have ongoing discussions with representatives of the business community who have expressed to me their concern about the gaps that exist in our society. They have indeed pledged to work with me to help find solutions. The same with some of the institutes here in Washington as well. We have also had input from the academic medical community as well.

We certainly are going to have ongoing input from each of these groups and members of my Department. The Steelman Commission that you will be hearing from later, also has representation from a broad spectrum of our society representing these groups and others as well. So, I fully agree with you that our recommendations, that we'll be coming forward with, will have input, not simply from members of my Department, but from those other segments of our society.

As I mentioned in my statement, this is not simply a Federal problem. This is a problem for State and local governments and the private sector. Therefore, we certainly need to have their help in finding appropriate solutions, ones that not only will stand the political battle of getting them implemented, but will stand the test of time of being workable programs, not Band-Aid solutions.

Representative STOKES. Thank you.

Thank you, Mr. Chairman.

Chairman ROCKEFELLER. Congresswoman Oakar?

Representative OAKAR. Thank you very much, Mr. Chairman.

Mr. Secretary, I was delighted to see you yesterday at the Mammogram Summit and I was delighted with your appointment. I was told by my good colleague from my hometown what a wonderful person you are personally and professionally and I've admired you at a distance for a long time.

Mr. Secretary, I guess I want to ask you something in a general sense, in a philosophical sense, because you mentioned private insurance in your statement. You seem to emphasize the private sector an awful lot in your statement. Long-term care policies, as you know, are very expensive and there's very few of them. I know you want to look to that, but that's a real problem.

But as a public policy, as the Secretary of what I consider to be in many ways one of the most important agencies for our country and one of the anchor issues affecting such a broad cross section of people, do you think as a public policy it's the Government's responsibility to have accessible health care for every American as a public policy?

Secretary **Sullivan**. Certainly I would agree with that statement. The one thing I would add is that we see this as necessitating participation by all segments of our society. That is, I do not see the Federal Government's role to provide all of that care. We have, as I mentioned, a very excellent system when it's working at its best. It's largely a private system. What I would like to see is to focus our efforts on how to improve that system because, as you know, in many ways when a problem can be addressed in the private sector, it can often be done more efficiently and more effectively than by the Government.

Representative **Oakar**. Well, if it's doing so well, why is our GNP higher than any of the countries, in terms of health costs? Of our GNP, 12 percent or more goes for health care, where it's about 7 percent for most of the other countries that have national policies. Why do we still have 37 million people with 1 out of 3 kids without any accessible health insurance, if it's so terrific?

Secretary **Sullivan**. Let me state this again because I perhaps didn't state it well. I said our system, when it's working at its best, really has no equal. But there's no question that we do have deficiencies in our system that indeed have resulted in those 31 million or 37 million uninsured, other gaps in terms of rural health care, our inner cities, and our emergency rooms being overwhelmed by patients because they have no other alternative.

So, I'm not saying that our system is working the way we would like to see it work or working the way we have the right to expect it to work. What I was saying is that the spread between what is possible versus what actually happens is indeed too great and that's unacceptable.

Representative **Oakar**. Doctor, thank you. You seem to put a lot of your emphasis on the Steelman Commission. Can you tell us who the other members of the Commission are? Do they represent a cross section of viewpoints in terms of their knowledge of Social Security, their sensitivity to those issues?

Secretary **Sullivan**. Yes. Ms. Steelman, I believe, will be testifying later and she can give the full range. But we have, for example, individuals such as former Secretary Arthur Fleming from HEW.

We have Dr. Lonnie Bristow from the American Medical Association representing physicians. We have——

Representative **Oakar**. Are the nurses represented or any other licensed health practitioners or older citizens groups? I have to say for the record I'm a little concerned, not individually, and many of these people are scholars, but viewpoints on some of these issues are a little bit out of the mainstream, I would think, of the areas that I think we would want to take a look at. At least I would, speaking for myself. I just think that one of the points that my colleague, Congressman Stokes, made or maybe it was the chairman, having a broad cross section of input not based on any kind of bent.

I know you're under tremendous pressures because you are part of a team, but I would hope that the people advising you would really represent a broad cross section of viewpoints, labor, management, that sort of thing.

Secretary **Sullivan**. Yes; we do have individuals representing labor. I don't have those names right here, but I'm sure that we can supply them to you.

Representative **Oakar**. And just one other quick thing and that is that I was delighted to see Barbara Bush at the Mammogram Summit. As somebody that offered part of the legislation, I was delighted to see it in the catastrophic health bill, which I think is not as bad as some people do. I am concerned about the regulations put out relative to this area of mammography coverage because they seem to adversely affect the spirit of the law. But if you could look into that as an aside, I would really appreciate it.

Thank you very much, Mr. Chairman.

Secretary **Sullivan**. Thank you.

Chairman **Rockefeller**. Thank you, Congresswoman.

Secretary **Sullivan**. Mr. Chairman?

Chairman **Rockefeller**. Yes, sir.

Secretary **Sullivan**. If I might, I do have now the list of the members of the Steelman Commission. I'd like to list them, if I might.

Chairman **Rockefeller**. If it's lengthy, Mr. Secretary, can it be distributed?

Representative **Oakar**. For the record.

Secretary **Sullivan**. Yes, we can distribute it. I would simply indicate that we have representatives of labor, of the business community. Dr. Dunlap, for example, former Secretary of Labor, professor at Harvard, the insurance industry and, as I mentioned, physicians.

I would have to say I don't believe we have a nurse on the Commission, but I can assure you we will have input from the nursing profession and other professions that we will indeed take seriously.

[The list of members referred to follows:]

Advisory Council on Social Security Members

Karen Ignagni, Associate Director
Department of Occupational Safety,
Health & Social Security
AFL-CIO
815 16th Street, N.W.
Room 306
Washington, D.C. 20006

John Sweeney, International President
Service Employees International Union
1313 L Street, N.W.
Washington, D.C. 20005

G. Lawrence Atkins, Director of
Employee Benefits Policy
Winthrop, Stimson, Putnam & Roberts
1133 Connecticut Avenue, N.W.
Washington, D.C. 20036

A. L. Singleton, Consultant
Webster, Chamberlain & Bean
1747 Pennsylvania Avenue, N.W.
Suite 1000
Washington, D.C. 20006

The Honorable James R. Jones
Dickstein, Shapiro & Morin
2101 L Street, N.W.
Washington, D.C. 20037

Professor John T. Dunlop
Harvard University
209 Littauer Center
Cambridge, Massachusetts 02138

Donald C. Wegmiller, President &
Chief Executive Officer
Health One Corporation
2810 57th Avenue North
Minneapolis, Minnesota 55430

Philip Briggs, Vice Chairman of
the Board
Metropolitan Life Insurance Company
11th Floor - Area G
One Madison Avenue
New York, New York 10010

Paul O'Neill, Chairman and
Chief Executive Officer
Alcoa
1501 Alcoa Building
Pittsburgh, Pennsylvania 15219

Theodore Cooper, M.D.
Chairman and Chief Executive Officer
The Upjohn Company
7000 Portage Road
Kalamazoo, Michigan 49001

Lonnie R. Bristow, M.D.
2023 Vale Road
Suite 6
San Pablo, California 94806

Mr. Robert M. Ball
505 Capitol Court, N.E.
#300
Washington, D.C. 20002

Chairman **Rockefeller**. Thank you, Mr. Secretary.

One final question from Congressman Gradison. I would point out that we are running, at this point, about one-half hour behind schedule.

Representative **Gradison**. Thank you, Mr. Chairman.

I'd just like to plant an idea, a seed, I hope. This is something I haven't discussed with my colleagues on the Commission, so it's just my idea. When we were working on the tax reform bill, the Ways and Means Committee took off for a weekend and in totally private sessions to talk about all aspects of the subject. At that time Secretary of the Treasury Jim Baker sat with us, visited with us for the whole weekend as a full participant in all the discussions. I'm talking about the economics of tax reform, the politics of tax reform, the tradeoffs of tax reform and it was extremely helpful to us. That was before we ever went into markup.

I'm not asking for an immediate reaction, but I think that's something that we ought to think about as we get closer to making our recommendations and plan to take some blocks of time, the possibility of your joining us on exactly that basis because I know it would improve the quality of our final report. I'm genuinely troubled by the walls that get built up in this town between the branches when we're all, I'm sure, seeking the same objective.

Thank you.

Chairman **Rockefeller**. Thank you, Congressman.

And, Mr. Secretary, we appreciate very much your taking the time to come. I also appreciate your waiting, although I'm sure that you also were very glad to hear what the previous panel had to say and concerned by it.

Secretary **Sullivan**. Thank you very much, Mr. Chairman, and I certainly do look forward to working with the Commission and sharing ideas with you. Hopefully, we'll come up with something together that we can be sure will effectively address these problems.

Thank you.

Chairman **Rockefeller**. Thank you very much.

We now shift to another segment which is the problem of long-term care. Briefly, we've had people discuss the problems of not having health insurance or having health insurance which is inadequate or a combination of both. Now, long-term care is a problem.

Our witnesses are Jim and Rebecca Schienle from Los Angeles, CA; Deborah and Scott Russell from Kalamazoo, MI; and Marilyn Rubin from West Hartford, CT.

This testimony, however, will be preceded by about an 8-minute film clip about Jim and Rebecca Schienle that appeared on Public Broadcasting. I think it's extremely important for people to see that and to understand that. That, of course, will be followed by Jim and Rebecca Schienle and the other panel members as they discuss this problem.

So, we now dim the lights and have the film clip.

[Film clip from documentary "Can't Afford to Grow Old" narrated by Walter Cronkite is shown and transcript follows:]

Rebecca Schienle. This whole house is structured on taking care of an 83 year old lady who has Alzheimer's disease.

Walter Cronkite. Loraine Schienle is one of 4 million Americans who suffers from Alzheimer's disease, the most common cause of severe mental impairment in people over 65. She is completely disoriented and needs the assistance of others to walk, eat, bathe, and change her diapers. Her son, Jim, and daughter-in-law, Rebecca, have looked after her for the past year in their home in Los Angeles, California.

Jim Schienle. From, I would say 7 o'clock in the morning until 6 o'clock at night when we put her to bed, that really, she can't be out of our sight for more than 5 minutes.

Rebecca Schienle. It's put a tremendous strain on our family. Jim and I cannot go anywhere alone together, or even together. When Loraine came to live with us Jason and Martin gave up their bedroom for her. And now Jason has no . . . he's a teenager. And he has nowhere to play his radio nowhere to go and talk privately on the phone with his friends. And when he wants to go to the . . . any priv . . . when he wants any kind of privacy, he has to go to the bathroom, and then, of course, we only have one bathroom.

Jason Dunfee. It brought out a lot of our problems and struggles and we've been able to get through them and this is a very big struggle.

Rebecca Schienle. Emotionally our children are suffering, but physically Loraine needs us. I mean she can't even brush her teeth. She can't even button a button. Where do we draw the line?

Walter Cronkite. Since Jim and Rebecca both work, they have to pay a home attendant $550 a month to care for Loraine 20 hours a week. The cost of Loraine's care along with the usual expenses of raising two children has caused the Schienles to go into debt and miss their mortgage payments.

Jim Schienle. Every month we go a little further in the hole . . . I mean got to delay all kinds of payments in order to make it work.

Walter Cronkite. Loraine qualifies for Medicare, the federal health insurance program for Americans over the age of 65. But, Medicare provides virtually no coverage for long term chronic conditions that afflict 1 in 4 elderly.

Loraine also qualifies for Medicaid, the federal and state health insurance program for the poor. Medicaid does cover long term care in nursing homes but rarely covers care at home. In fact, Medicaid spends 11 times more on nursing home care than on home care. Since Medicaid won't cover help for Loraine at home but will pay for her to live in a nursing home for the rest of her life, the Schienles feel that they have no choice but to place Loraine in a nearby nursing home.

Jim Schienle. We've found a place you know, here people can take better care of you day and night. And it's going to be real close. And tomorrow morning we're going to go there. OK? Do you understand?

Loraine Schienle. Yeah.

Jim Schienle. Okay. Would that be OK with you?

Loraine Schienle. Sure.

Jim Schienle. Okay.

Rebecca Schienle. If we could afford to have someone in here eight hours a day, we would keep her here until she passed away.

Jim Schienle. Plus she'd get the one thing that we really think is critical, and that's to be loved until the moment she dies. I'm just angry at myself for not being able to take care of her on my own. You know, I don't really hold it against the government not giving me money. I think if I had my act together, I'd be making enough money to be able to do it. And I'm not.

Are you going to sleep good tonight? I love you very much. Good night.

Rebecca Schienle. Jimmy, are you sure you want to do this?

Jim Schienle. I feel like I'm letting her down. Although she doesn't seem to be aware . . . do you Mom?

Rebecca Schienle. Do you know where we're going?

Loraine Schienle. A ride.

Rebecca Schienle. For a ride. Yep, we're going for a ride.

Jim Schienle. We couldn't afford to take care of her in the way we have to. We couldn't afford the help we need. I've been feeling very angry. Real hard to deal with, hard to talk to. And real guilty. And I think it's all related to having my mom go somewhere where people taking care of her there are not taking care of her from their heart.

Nurse. She may be a little bit confused and a little bit disoriented as to where she is. And they will tell the families especially . . . well, I want to be home. I want to go home. But after a while, they get adjusted.

Jim Schienle. Are you a little nervous about being here?

Loraine Schienle. Yeah.

Jim Schienle. Yes. Can you lay back and relax?

Loraine Schienle. No.

Jim Schienle. No. You want to sit up, huh?

Loraine Schienle. Yeah.

Jim Schienle. Okay. So we're going to leave, but we're going to come back this afternoon to see you again.

Loraine Schienle. How long do I stay here?

Jim Schienle. They just need to do a few things to take care of you. They want to take care of you for a little while. Okay? And we'll keep coming back.

Loraine Schienle. No you won't.

Jim Schienle. We'll keep come . . . oh yes we will. We'll keep coming back. We'll see you later.

Rebecca Schienle. Bye. We'll see you later.

Jim Schienle. Bye Mom.

Rebecca Schienle. It makes me very angry that we're forced to literally put her away because we can't afford to keep her anymore. And she deserves to be taken care of in her golden years. And the way the government is structured, they are put out to pasture like cattle. And we're all going to be there one day. Unless we do something to change it.

[The film clip is concluded.]

Chairman **Rockefeller.** Jim and Rebecca, we're very glad to have you here and we admire your courage for not only educating us through the film, but also through what you will be talking to us about. We welcome your testimony.

STATEMENT OF JIM SCHIENLE, LOS ANGELES, CA

Mr. **Schienle.** Chairman Rockefeller, members of the Commission, my name is Jim Schienle and I'm from Los Angeles, CA, and I'm here today with my wife, Rebecca.

As you could see from the film, this was a tremendously difficult time for our family, full of conflicting emotions. On one hand, this was my mother. I felt the responsibility that many others in my situation probably feel. She took care of us, now it's our turn. I couldn't help but feel, to some extent, that I was letting her down.

On the other hand, taking care of mom was beyond our capabilities. We couldn't handle it ourselves and we couldn't afford to buy the help she needed. Rebecca left work to care for her. There was more expense and less income. Our home barely met our needs before mom came to live with us. Afterward, there was no privacy. Rebecca and I had one bedroom, my mom had the other, and our sons slept on couches. We couldn't afford the planned expansion to our home which would make the situation workable.

At the end, mom's care was becoming more demanding. She needed to have her diapers changed five to six times a day. At night, we had to use a restraint. We felt terrible about doing this to her, but we didn't know how else to keep her in bed. Finally, we reached our limits.

We were fortunate to find a decent nursing home. Most homes don't find MediCal patients profitable. Many of the places we visited seemed as though they were just taking care of bodies. The patients sit in a big room so that one or two aides can keep an eye on all of them. One home smelled strongly of disinfectant. The home we found for my mother is near the ocean. It's airy and the staff is cheerful. Still, after I first put mom there, I felt tremendously guilty. I wouldn't go for weeks at a time. Every time I'd go, she'd want to come home with me. When I did go, I wouldn't stay long. I didn't know what to say. There didn't seem to be much to say, so we'd wind up just sitting.

Although she's not suffering as much now, there's not much left of her. She's just a person who sits in a wheelchair. Sitting with her didn't seem to me to be a very productive use of time. But my wife pointed out that this might be just what my mother needed. She does recognize me when I visit. Now I go quite often, sometimes daily.

All in all, even though it's hard, we'd like to be able to have her at home. Having the kids and the dog and people who pay close attention to her would make her life better, make her more responsive, the way she was when she was at home. With some assistance, home care or adult day care, we could have her home with us.

I hope that the Pepper Commission will provide some answers to the problem of long-term care so that when other families are confronted with the problem of caring for their parents, their decision will be less traumatic and they will feel less helpless because they have real choices.

Thank you.

Chairman ROCKEFELLER. Rebecca?

STATEMENT OF REBECCA SCHIENLE, LOS ANGELES, CA

Mrs. SCHIENLE. Thank you very much. This also is a very emotional subject for us, so please bear with me.

Placing Jim's mother in the nursing home is the hardest decision we have ever had to make. It was emotionally wrenching. We love her very, very much. Even though we had to structure the whole house around caring for her, we felt it was the right thing to do. But we were in a totally impossible situation. Emotionally, we had the desire to keep her at home, but financially and physically, it was completely impossible.

Moving my mother-in-law about was hard on me. I broke my back as a teenager, so it was extremely difficult for me to lift her. She didn't know to help by pushing up. She was like dead weight.

Toward the end, everyone was suffering. The kids were suffering and we were in jeopardy of losing our home. I knew she wouldn't want that. She was requiring more and more attention and we had no idea how to care for her. I felt she was suffering. We tried to get help but there was nothing available. Believe me, giving her up was a last option, but we felt we had no other place to turn.

After we decided we'd put my mother-in-law in a nursing home, we didn't rush out to find one. We took our time. We did not really want the responsibility of making that decision. Then one day I took her to the doctor and he took one look at me and one look at her and said: "She has to go into a nursing home." Jim screamed and yelled and said he wasn't going to do it. I said I wasn't going to do it. But, of course, we knew we had to.

I'm still really angry about having to put her in the nursing home. But I don't know who to blame. Did we fail her? Did you fail her? Did the Government fail her? I don't know. I do know that our older people have contributed their whole lives and they deserve to be taken care of. We are all going to be there one of these days and when I get there, I don't want to be in an old folks home. I want to end my days with my family, just like she wants to.

If we ever get to the point where we can handle it financially, we would take her out of there in a second. Excuse me.

Chairman ROCKEFELLER. Take your time, Rebecca.

Mrs. SCHIENLE. Even with the house as it is, without the expansion, we would bring her home again if we could. Giving her up was devastating to us. No family should ever be forced into that situation.

Thank you.

Chairman ROCKEFELLER. Thank you both very, very much. Maybe it would be good if we just questioned the two of you before we went on to the others.

I think it can be nothing but clear that you both have suffered enormously in this process. Let me put it this way, I'm not sure that all nuclear families would have fought to the last and struggled as hard to make the decision. There's the phenomenon in our country I think we're all aware of sometimes that families don't take responsibility for their mothers or their fathers. You clearly did, however the system, for whatever reason, prevented you from being able to do what you wanted to do, which was to keep her home.

Now, with that in mind, were there—in terms of let's say home care, and I agree with you. That's where people want to be. That's where you want her to be. It's very clear when she wouldn't lean back in her bed, she didn't want to be there, and her hands were shaking. It was all so clear.

Did you have services available? Had you been able to afford them, were there services available in your area where you could have had home care, a visiting nurse, a variety of those things, or was it a matter of simply not being able to afford it even if it was available?

Mr. SCHIENLE. Visiting nurse would definitely require us to pay for the service, which gets excessive over a period of time. There are nursing home care capabilities which are funded, but they're for acute home care. So, we did get some of those services for mom for a short period of time when she returned from the hospital. But for any kind of chronic needs, those services are only private and just require tremendous amounts of finance.

Chairman ROCKEFELLER. What are the implications of all of this to both of you financially?

Mr. SCHIENLE. Well, you know, it's not only this actually. It's a lot more difficult to make it financially these days, period. Health care is part of the problem. I think that in the health care area, that the cost of health care is really a big part of the problem. Not so much what can we do, but it costs so much to do anything. I may work for a week just to be able to afford some kind of medical care that isn't actually very significant and requires a tremendous amount of my income to do it.

We have some debts now from my mother, some of which may never have to be paid because they were debts to her. While we'd like to pay them, we may not have to do that.

We still have costs, actually, of about $400 or $500 a month. We do have to pay some of her care in the nursing home which isn't covered by MediCal and we also pay a lady to go in there 2 days a week who became a friend of hers while were taking care of her at home. She stays with her for about 4 hours each of those 2 days and it's tremendously valuable to my mother because we can see what happens with other patients where that doesn't happen. So, we still have costs and we don't have any money in the bank, I'll tell you that.

Chairman ROCKEFELLER. Can you describe for us, more than what you described in the film clip, about the costs emotionally, the pressures within the family, the pressures on your children, the giving up of the room, and other things? What was the cost—I don't mean disintegration of the family. I'm not going that far because in some ways it brings you closer. You two are so unbelievably close to each other and to your mother in any event. But what happened? What is the pain within the nuclear family for this kind of pressure?

Mrs. SCHIENLE. It was extremely hard on Jim watching his mother deteriorate. When she first came to live with us, she was still able to move about. We didn't let her cook. She wasn't too good about that. Within the year that she was with us was when she became real bad. She was in diapers. There were times when she didn't know who we were. She became paranoid, accused our children and us of stealing from her. We would have to take the children aside and explain: "Grandma didn't mean that." Yet here they are standing wide-eyed and innocent: "Grandma has accused me of stealing her purse." But here we have children who are suffering and then we have this little old lady who strongly believes what she's saying. So, we had problems from both ends, the young and the old, and it was extremely hard to balance the two.

Mr. SCHIENLE. Physically, it's also just real hard to take care of her because she needs attention all the time. I mean you can't turn your back or she will try to stand up or something and then hurt herself. One night she got out of bed during the night, fell down, broke her collarbone. Then it's ambulance, into the hospital for a few days, and back and forth to the doctor. So, that's why we used that jacket to keep her in bed.

So, just physically, unless we had a situation where she could sometimes have her own space that would separate her a little bit from the family so we could all take a deep breath and have an hour or two without that responsibility, it's very hard. If our home was big enough, if we had another bedroom and we had somebody who'd be there with her and for a little while we could separate the two groups, that would make it livable. Then it could work.

Chairman ROCKEFELLER. The pain of taking her to a nursing home was obvious. The pain of having her at home was also obvious in some ways because of the effect on your children. Just the question of respite care—something to give relief. What you both want is to be able to keep her at home if there were a way to afford that. How would your kids deal with that? What would be the disruption to their lives that would make it—that even so it would be worthwhile to have her there? I'm asking you a sensitive question. I understand that.

Mr. SCHIENLE. If we had space, if we had some room to spare, it made us a much richer family. I mean we may tell you about our problems, but actually we enjoyed the experience tremendously. We benefited tremendously from the experience and she contributes and did contribute very, very much to our family. So, in no way do we want to seem like victims of this because it's been a very rich experience for us.

The value of having her home, which is much richer for us, than having to have her be somewhere else where people probably aren't getting as much value out of it and where we're probably spending, as a country or as—you know, the expenses are still there for her, so we're still spending the money, but we'd like her to be home instead of there. The services aren't available at the moment to give her that care at home. I mean we really explored that and there were always conditions that we didn't meet or we couldn't have a lady long enough or she could come for 3 hours but not for 8. You know, the funding just had a lot of holes in it that didn't recognize the value of spending the money in another way.

Chairman ROCKEFELLER. Thank you, Jim.

Congresswoman Oakar?

Representative OAKAR. Thank you, Mr. Chairman.

And I want to thank the witnesses for a very important story. It's probably no consolation, but you're not alone. There's thousands of people just like you.

Mr. Chairman and members, it was interesting in the Cleveland hearings of this Commission in my hometown. We had a woman with a very interesting story to tell. Her mother has Alzheimer's disease and her mother-in-law has Alzheimer's disease but her mother-in-law lives in Canada and she lives in Greater Cleveland. I mean the difference in accessible assistance to the families is just unbelievable. She is traumatized personally in the same way that you are and yet her mother-in-law's family does not have the same problems in terms of accessible services.

Let me just ask you this. If you had even some form of homemakers service—you mentioned you had a bad back as a matter of fact—do you think you'd always need a licensed health practitioner in terms of your home? Would homemaking services be helpful or somebody to watch your parent while you were gone? Would that be something that would be helpful to keep your mother and mother-in-law at home?

Mr. SCHIENLE. That's what we used when we had her at home. It was really just a matter of how much we had to have her there and then how much we could afford. But that's tremendously adequate.

Representative OAKAR. Would that, in and of itself, be enough to keep her at home?

Mr. SCHIENLE. That and we'd, I guess, debate the space problem a little bit.

Representative OAKAR. The what? I'm sorry.

Mr. SCHIENLE. The space problem, being able to separate ourselves once in awhile.

Representative OAKAR. So, in other words, if you had some respite care, you had some opportunity for some respite of this yourselves personally for the sake of the family, or be able to put your mother on occasion into a respite center, that would be helpful to you, right?

Mr. SCHIENLE. It's hard to move her now because she's 84 and doesn't get around very easily. But the kind of care does not need to be medically qualified.

Representative **Oakar**. Thank you, Mr. Chairman.

Thank you.

Chairman **Rockefeller**. Dr. Davis?

Commissioner **Davis**. Thank you, Mr. Chairman. I simply want to commend Rebecca and Jim on the courage it took for them to come today at even an additional emotional expense, and to tell you that I'm convinced that your appearance here today plus your film is going to be an invaluable help to all of us as we collectively work trying to solve this very difficult problem. We thank you very much for being with us.

Chairman **Rockefeller**. I might point out that the film clip that you saw will be shown on public television on October 4.

Jim and Rebecca, thank you very much.

To either of the other two remaining sets or individual panelists, I don't wish to diminish what you are going through because your stories are potent and deep to exactly the same extent.

Deborah and Scott Russell are from Kalamazoo, MI, and we would welcome your testimony.

STATEMENT OF DEBORAH RUSSELL, KALAMAZOO, MI

Mrs. **Russell**. Good morning. I'm Deb Russell and this is my husband, Scott, and our two children, Margaret and Daniel. Scott and I are going to share our testimony today also.

We appreciate the opportunity to come before you and share our family's experience with the long-term care needs of our son.

When Meg and Dan were born, they were 7 weeks early and they weighed 4 pounds. Meg had a correctable heart problem and she's now doing fine, but Dan has life-threatening problems with his airway which he's had since birth. He spent 5 months in the neonatal unit in our own community and 3 hours away in Detroit before he could come home. His breathing problems come from a congenital defect in his trachea, his breathing tube. A section of it collapses and shuts off his airway and then freezes into that position. He has to go into an operating room to have it reopened.

For the past 7 years, he's had a specially sized tracheotomy tube to hold his airway open and he breathes through this. He's had over 30 surgical procedures on his trachea and he will require a major surgery, hopefully, when we can get to that, that will remove a section of his trachea. They'll have to open up his chest and put him on a heart/lung machine to do it.

Until then, he has to be monitored around the clock by someone who understands when he needs suctioning of his trachea or more humidity. His trach is suctioned periodically, approximately every couple of hours, and he needs respiratory treatment and chest physiotherapy, and more of it when he's ill.

In addition to his respiratory problems he has stomach problems. He has lung damage. His vocal chords were destroyed and when he came home he was diagnosed as failure to thrive. He only weighed 12 pounds when he was 1 year old. He wasn't even on the growth chart.

His problems have meant more surgery. He's had two surgeries on his stomach, one of them this summer, and two to rebuild his larynx and upper trachea using skin and rib cartilage grafts.

As a result, Daniel requires nursing level care around the clock. We've had emergencies at home where we've had to intervene so that Dan could live and breathe. Often you have to be able to respond before an ambulance could even get there and certainly before you could get to the hospital. Although our family, Scott and I, provide much of this care ourselves, Dan's medical costs are still around $200,000 a year. But we are absolutely, totally committed to having him at home.

I guess I just want to comment here that when I was—after my senior year of high school I worked in nursing homes to support my way through college and it was at that time that I decided that I definitely wanted to go into gerontology and do something about people having to live in nursing homes. It was just a terrible shock to have our experience with having our first children be one where nursing home care has been threatened.

Taking care of Dan has had a profound impact on our family life. For 2 years, Dan did not leave our home except to go to the hospital. We became isolated. My husband and I actually did get to the point where we were arguing over who got to go out to the grocery store. We couldn't do anything special with Margaret until she was 3 years old. She finally got to have swimming lessons and at that point they wouldn't let the moms go with the babies and I really kind of grieved over that.

For years we couldn't go to church or to a friends house for dinner or to an outing. It was even too stressful to have people over to our house because of the kind of vigilance that he required. Neither of our kids could go to day care or nursery school because of Dan's susceptibility to infections. Activities had to be done so that we could hear and monitor Dan at all times and this restricted our normal activities such as taking showers, doing laundry, running the vacuum, or listening to music.

Because we had to concentrate on taking care of Dan, we couldn't be there for our family and friends. I don't know—I guess I hadn't realized what a terrible hurt it is not to be able to give to other people when you're kind of used to the give-and-take of family life. My mother had a heart attack when Dan was 1 year old and I wasn't able to help at all. Now my dad, this summer, has been diagnosed with lung cancer and I don't know how much I'll be able to be with him and my mother and my sisters. It's very painful.

Our careers and our choice of employers and our geographic mobility are limited. My ability to work has frequently been threatened. As some of the other people who have testified, you can see we don't feel we have the option for us to become self-employed or to even work for a small employer or to move to another State.

We worry constantly over the payment for Daniel's health care, particularly now that we're going to an out-of-State specialty center which would be difficult to cover through Crippled Children's in our State. We worry about the home care.

Although working mothers are the norm today, my need and my right to work is routinely questioned by the payers for Daniel's home care. This even occurred when I was the sole wage earner and insurance holder for our family and I actually ended up having to quit my job before my husband's insurance could start covering

Daniel and all of his bills were on Medicaid instead of just part of the home care bills.

Over the years, Dan has been covered by private insurance, Crippled Children's and Medicaid waiver programs. Every single month that I have worked, I have had to buy and contribute toward our coverage either because I was part time or because my employer didn't offer dependent coverage. Even when we've both had insurance, we've been so determined that we would have it some way privately that we've been willing to do that.

It doesn't seem to matter who's paying, we always end up with the same problems. We have to fight with the health care coverage provider constantly over the home nursing care, even though it's ordered by our son's doctors and even though it's a benefit under the plan.

We are Daniel and Meg's parents 24 hours a day and we wouldn't have that any other way. But we shouldn't have to be medical slaves, giving up all other activities. The payers who authorize care seem to feel that if our family is not in crisis, we must be getting too much home care for him. After 7 years, we know that we can't live on the edge like that.

STATEMENT OF SCOTT RUSSELL, KALAMAZOO, MI

Mr. **Russell**. Right now, Dan is on an insurance policy through my job. But he's nearly exhausted his $500,000 lifetime limit. After that, we plan to have him covered by Deb's policy. She's employed through a grant which ends in 1 year. We had assumed that under COBRA [Consolidated Omnibus Budget Reconciliation Act] we would be able to purchase a continuation of the coverage, but we've discovered that we're not eligible to purchase COBRA coverage if he's covered under another policy. This means in our case that if he's listed under my policy, even though the benefits are exhausted, COBRA will not apply to him. It also means that if I quit my job and find a new one for which he would be offered insurance benefits, he would lose COBRA coverage as soon as he's listed on another policy, even if there's a waiting period or exclusion for his preexisting conditions. So, COBRA offers us no protection.

This also prevents us from participating in a special Blue Cross/Blue Shield individual policy that Michigan requires.

As you can see, our private options are likely to fail soon, so we've put Dan on the waiting list for a Medicaid waiver in our State. But there are a limited number of slots and a long waiting list. We agonize over and over again, wondering what are we expected to do?

We've been trying to raise our children and help them become responsible and productive citizens. Dan attends community schools. He has for 3 years now. He plays soccer and we feel we've given them a good quality of life. We've tried to purchase health care and provide for those kinds of needs but we just can't figure out how to do that.

Ours is not the worst case of a family trying to cope with a child's long-care needs. We each have lots of benefits. We each have two college degrees. Deb has a background in human services and long-term care and works for a public employer with flexible benefits. I work for one of the 100-best companies to work for with a reputation for taking care of its people. We live in a State known for its progressiveness in human services. How much worse it must be for families who love their child just as much as we love ours, but lack all the advantages that we have.

We, as sophisticated and motivated consumers, have found that health care financing system is just totally unworkable. It doesn't seem right that these children should not be given the opportunity to live and thrive within their families.

Thank you.

Chairman ROCKEFELLER. Thank you both very, very much. Those are beautiful children and you're a beautiful family.

You've been under private insurance. You've been under Medicaid waiver. Did you find any difference in the quality of assistance and help that you got between those two?

Mr. RUSSELL. In both cases we've found that it was a struggle, that there was always a pressure to reduce cost and to save and you always had to continue to challenge and to actively pursue getting the appropriate benefit. I think that it was perhaps more difficult and more stressful under Medicaid, but it's not automatic in either case.

Chairman ROCKEFELLER. Yes. In what way?

Mrs. RUSSELL. Well, I think one of the ways was that your life is just totally an open book. You have to—every intimate detail of your life and your finances is under scrutiny and you're second-guessed at every turn. I felt, especially as the mother who I think there's a lot more expectations on of—I mean mothers are a bottomless pit of giving to their children—that there was a lot of judgment about whether we were doing enough. That hurt me very much because I felt that we were doing the most we could.

Another issue that's come up is that in our community there's only one nursing agency that will accept Medicaid and they have even begun to say they can't take anymore. They can't take anymore kids on waivers because they lose so much money on those cases that they've exhausted their United Way funds. So, there is a question as to whether we'll have the same continuity of agency if we go. The provider that we have now is the original agency that provided Medicaid coverage and after a couple of years they got out of it. So, it looks like we may be changing agencies.

Chairman ROCKEFELLER. This leads me right into the question of if you had to go back to the Medicaid waiver, how long do you think it would take you to be able to get and how long would you be on the waiting list, do you think?

Mrs. RUSSELL. Well, the waiver that we had—we actually had two waivers in our State and we were on the original one. That one is now not a waiver anymore, it's the TEFRA Program where you can individually cost—if you have no insurance for hospitalization, then the child would be eligible. We probably won't fit that one.

The other one is administered through the department of mental health and it's limited to 200 slots, I believe. I was recently involved with some other parents in advocating that the full amount of matching dollars be allocated by our State legislature to match those dollars. We haven't yet been completely successful. So I know that for most families there's about a 6 month wait when they're given permission to apply. It can take up to 6 months. We haven't been given—we're not in the group that's being given permission to apply yet.

Chairman **Rockefeller**. I really thank you both very, very much. There are a thousand questions to ask and no time now. Again, I have to say that you're an extraordinary family, the way you've fought, the way all of you have for your family members is remarkable and it's what this country is meant to be about.

What this country is also meant to be about is for you to be able to find a way to get through all of this. We seem to be coming up short.

Marilyn Rubin, I'd be very interested in your testimony.

STATEMENT OF MARILYN RUBIN, WEST HARTFORD, CT

Mrs. **Rubin**. Thank you, sir.

Chairman Rockefeller, members of the Commission, my name is Marilyn Rubin. I live in West Hartford, CT, with my husband Bill, my son Brett who is 16, my daughter Lisa who's 13. But it seems they really haven't been children for a very long time. My husband has multiple sclerosis [MS] and it takes a total family effort for us to cope.

Bill was diagnosed with MS 24 years ago, when he was still a teenager. When we were married, 5 years later in 1970, his condition was still not apparent. But by 1981, he had to leave work. He was a salesman on the road. He used a cane and he was getting in and out of the car. It was becoming very difficult. He has been using an electric scooter since 1982.

Over the last 5 or 6 years, his condition has deteriorated considerably and he is now a paraplegic. Caring for Bill presents certain challenges for our family. First of all, he's a foot taller than I am. There is no way that I can lift him by myself, though I frequently do. For the last few years, our son Brett has not left the house without leaving a number where he can be reached. If my husband has to go to the bathroom, Brett comes home from wherever he is, a date, a party, anything, to transfer him onto the toilet, to wait until he's finished, and to lift him back off before going back to whatever he was doing.

MS is a chronic illness. To you, that may mean a condition which exists over a long period of time. To our family, chronic means it's with us all the time, every hour of every day without a break. It doesn't matter where you go, it follows you. It actually haunts you. It means you can never plan ahead to do anything. You have to wait to find out whether this is going to be a good day or a bad day. Most families can plan a vacation and they can get away from whatever problems they might have. They're so lucky. For us, there is no vacation.

Since MS is a degenerative disease, he will continue to go downhill. Because of this, his urologist recently suggested that we look into a nursing home for him. As we started looking around, the homes all said exactly the same thing, you don't want to put him in here. Part of it is the fact that at 42 he's so much younger than the rest of their residents. It's also because they know that his condition will deteriorate to the point where he will require one-on-one, around-the-clock care, and nobody wants to handle that.

Instead, several directors have suggested Connecticut's Prescreening Admission Program. Under this program, a medical person, usually a nurse, and a social worker come to your home, assess the patient's needs, and provide aide services to help you care for your family member at home at a cost of perhaps $20,000 a year to Medicaid as opposed to $50,000 plus a year for nursing home care. In my State, nursing homes run between $50,000 and $60,000 a year. Not to mention the fact that we could remain a whole family, if we could get into this program.

Well, we were really excited about this. We don't want Bill in a nursing home yet. This program seems like the perfect solution for us. The problem is that in order to be eligible, you have to be 65 years old. If he lives another 23 years, Bill will be eligible for this wonderful program. We can't wait 23 years. Most likely, Bill will be gone in 10. We need help now so that we can enjoy these last years.

I really am lucky, I think, although most people would not think so looking at my life. Despite my husband's illness, we're still a close family and we do a lot together. Bill still goes to Brett's football and baseball games and Lisa's softball and soccer games and he cheers from the sidelines. A lot of other fathers don't make the effort.

I'm grateful for our children, who have wanted to help in any way they could from the very beginning. Even though there is so much divorce out there, here are four people who really want to stay together, but there is no agency or program to help people like us. If you're a young person with chronic illness in need of long-term care, there is no program in place, none. We are really trying to keep our family together against so many odds.

Consider us, please, on our needs, not on our age, not on our income. There are 9 million chronically ill people and there are many well spouses and families attached to these people. I'm not here today seeking your pity for the state of my family, or your praise for how noble we are in dealing with Bill's illness ourselves. My message to this Commission is that this is not just a problem for the elderly. I've heard so many people say this is an elderly problem who are experts here. Please understand, elderly people have problems, middle-aged people have problems, and young people have problems. This panel here shows you the range of need.

Chronic illness hits younger people too. There are millions of other families out there like ours, not only with MS but with many other chronic diseases who are trying desperately to cope with this kind of problem on their own. I hope you'll remember us when you make your recommendations on long-term care. I rarely bare my soul and it is less often that I complain. I thank you all for listening to me and I am so very thrilled at the thought of you, who are in power, caring enough about those of us living with chronic illness to give me this chance and so I trust you.

Thank you.

Chairman **Rockefeller**. Thank you very, very much, Marilyn.

The point you make is so much on target, that when people think of long-term care, they tend to think of somebody 65 years old and that's absolutely part of the problem. But as you indicate, the panel today shows that it's a lot more than that, too, and that it starts very young, chronic, lifelong. It's massive.

If you were able to get the kind of services in your home that you described in your testimony, would you be able to care for your husband for a much longer period?

Mrs. RUBIN. Yes, for sure.

Chairman ROCKEFELLER. Is there any way for you to afford the home care yourself that you need?

Mrs. RUBIN. No; we have lived with multiple sclerosis for over 19 years. I have two children. I have a mortgage. I have loans over my head. We built an addition onto our home. I borrowed money so that my husband could live in it. We live in a split level. We have stairs every place. I have a van with a lift so that Bill is not trapped in that house and can be a part of this family. That was also done with begging.

It's very difficult to ask for help. It has become a way of life for us. It is a horrible thing to have to go before groups of people and say: "I need help." I hope that this body of people before me can actually do something to help us before it's too late. I go to lots of different groups and I ask all the time. I just can't seem to find the right group. I don't think there's anybody out there who can fill my need.

Chairman ROCKEFELLER. Marilyn, thank you. What comes through to me, one of the many, many things that comes through to me is that sometimes in our country either policymakers or bureaucrats or sometimes our people—some of our people think that if there's something wrong with somebody in a family, that somehow that family ought to be able to take care of it and if they can't, that somehow they are deficient.

What the three of you, representing three different families, are saying is that the strongest, most determined, just resolute effort to overcome, to persist day by day for as long as you can, isn't always enough. There is no intention of trying to pass this off to somebody else or to pass it off to a program which doesn't exist. That is the last thing you want. You want to be able to do it yourself, but you simply can't and it's no deficiency on your part.

I mean you say you don't want to be praised. Well, you will be praised by this Commission member. What is so utterly fascinating in this incredible system of ours, which is so far in advance of anybody else, has such enormous gaps through which people with substantial and varied education and incredible determination like yourselves fall. It's part of our job—you've contributed immeasurably, all of you, and I thank you all very, very much.

Mrs. RUBIN. Thank you.

Chairman ROCKEFELLER. I indicated before that we have fallen behind schedule, but I think in good purpose. I'm going to make a change in our order. I'd like now to have our labor/management panel come forward and give their perspectives on this problem which, in fact, is both problems. That is long-term care and the uninsured.

John Sweeney, president of SEIU, and chair of AFL-CIO Health Committee and also Walter Maher, who has testified before in our long-term and Medicare Committee and Finance Committee, who is director of Federal relations for the human resources office of the Chrysler Corp.

We made this panel change specifically with a time problem in mind, John, and I would welcome your testimony.

STATEMENT OF JOHN J. SWEENEY, INTERNATIONAL PRESIDENT, SERVICE EMPLOYEES INTERNATIONAL UNION [SEIU], AFL-CIO, CLC AND CHAIR, AFL-CIO HEALTH CARE COMMITTEE

Mr. **Sweeney**. Thank you, Senator and members of the Commission.

Chairman **Rockefeller**. And you might introduce Peggy too, which I failed to do.

Mr. **Sweeney**. Sure. I'm John Sweeney, president of the Service Employees International Union and chair of the AFL-CIO's Health Care Committee.

Chairman **Rockefeller**. John, could you get that microphone up close, please?

Mr. **Sweeney**. Sure.

Chairman **Rockefeller**. Thanks.

Mr. **Sweeney**. With me is Peggy Connerton. As you said, Mr. Chairman, I have a time problem. So if Peggy could answer the questions maybe after we both give our testimony here.

I'm here on behalf of the 14 million members of the AFL-CIO. I thank the Bipartisan Commission on Comprehensive Health Care for the opportunity to appear today.

The labor movement, as you know, has played a major role in developing the private insurance network through its coverage of some 65 percent of all Americans is the backbone of health coverage in our country. But today, skyrocketing health care costs threaten to dismantle the employment-based insurance system. There's no relief in sight from these mounting cost pressures. If trends continue, health care expenditures could double by 1995 and triple by the turn of the century.

Organized labor confronts this health crisis daily at the bargaining table. Bargaining affordable family coverage in low-wage industries is an uphill battle. Even maintaining affordable benefits won years ago for middle-income workers and retirees gets harder and harder. During the first round of double-digit premium inflation in the early 1980's, labor and management work together to contain costs. Many innovative programs were introduced such as hospital utilization review, managed care and for awhile they seemed to hold down health cost inflation. But today, health costs are rising faster than ever. In 1988, they were up 20 to 30 percent.

Many employers have given up on controlling costs and are shifting the risks of health inflation to workers. Cost shifting, disguised as cost containment, is what's forcing workers in increasing numbers to the picket lines. The 5-month strike by the United Mine Workers centers on Pittston Coal's attempt to force workers into a new insurance plan that would require deductibles and sharply increased coinsurance for family coverage.

Across the country, management attempts to move health costs off their books and onto workers paychecks is the top strike threat. The communication workers and the electrical workers recently concluded negotiations with AT&T where the key issue was health costs. Despite years of union management containment efforts, AT&T's health costs had topped $1 billion a year. The settlement included a historic commitment to work jointly for national health reform. What they did amounted to a plea to get the question of health coverage off the bargaining table and into Congress.

In order to gauge the impact of cost shifting by service sector employers since 1987, our union surveyed a sample of plan options covering roughly one-fifth of our membership. The study paints a bleak picture. Among the major findings, first, health coverage obtained through private insurance for middle-income workers is in grave danger due to a large jump in the worker paid share of coverage costs. Worker premium contributions for family plans rose twice as fast as employer contributions. Deductibles and copays followed suit.

As a result, middle-income families in indemnity, or PPO [preferred provider organizations] plans, face the threat of medical bills as high as 20 percent of after-tax income, an unacceptable level of risk.

Second, low wage service workers in the private sector are even worse off. Although technically insured, their coverage is financially out of reach. The survey results point out an important missing dimension in the health policy debate. It's not only the 37 million uninsured people who face barriers to access. Millions more have job-based coverage only on paper.

Our study also shows that while cost control measures implemented in the early 1980's, lowered health costs below what they otherwise would have been, they haven't achieved ongoing savings.

The labor movement will continue to bargain aggressively to hold the line on health benefits while working with management to achieve genuine cost savings. But we must not delude ourselves. It's not the long-run solution to our Nation's health crisis. With thousands of public and private health plans, cost containment amounts to little more than each plan trying to shift costs elsewhere in a vicious cycle. And employers that don't provide health coverage at all are getting a free ride.

The labor movement will continue to support incremental efforts to expand Medicaid coverage and the Minimum Health Benefits for all Americans Act introduced by Senator Kennedy and Congressman Waxman. But further action is necessary before the private insurance system collapses. We need, in short, systemic reform carried out at the national level.

In recent months, many comprehensive reform proposals have surfaced. Polls show that the most popular choice is to expand our mixed public/private system to guarantee access for all. The primary issue for policymakers is whether to rely on Medicaid or mandated private insurance to cover the low-income working population. To succeed, this approach would require simultaneous action to build up the public and private insurance systems to conserve public dollars while insuring that no one is left out. It must also be accompanied by private insurance reforms and a cost containment program as well.

The other major alternative is a modified Canadian-style system with Government-based financing and private delivery of care which is best exemplified by the Health Security Partnership Plan put forward by the Coalition for National Health Insurance.

The appeal lies in the combination of unqualified universal access with the proven ability to control costs. I urge the Commission to weigh all the reform proposals carefully and to bear in mind the lesson of labor's experience in recent years that voluntary private insurance is falling substantially short of the mark.

The Pepper Commission is in a unique position to break the policy logjam. I know the Commission is equal to the task and you have our best wishes for success in your endeavors.

Thank you very much.

[The prepared statement of Mr. Sweeney follows:]

SERVICE EMPLOYEES
INTERNATIONAL UNION, AFL-CIO, CLC
1313 L STREET N.W. • WASHINGTON, D.C. 20005 • (202) 898-3200

JOHN J. SWEENEY
INTERNATIONAL PRESIDENT

RICHARD W. CORDTZ
INTERNATIONAL SECRETARY-TREASURER

Testimony of

John J. Sweeney, International President
Service Employees International Union, AFL-CIO, CLC
and Chair of the AFL-CIO Health Care Committee

on behalf of

American Federation of Labor, Congress of Industrial
Organization, AFL-CIO

before

The Honorable Jay Rockefeller

Chair

U.S. Bipartisan Commission on Comprehensive Health Care

on

"Long-Term Care and Access to Care:
Defining the Scope of the Problem"

September 21, 1989

36

I am John J. Sweeney, President of the 925,000 member Service Employees International Union, and chair of the AFL-CIO's Health Care Committee. On behalf of the 14 million members of the AFL-CIO and all working Americans, I want to thank the Bipartisan Commission on Comprehensive Health Care and its new chair, Senator Rockefeller, for the opportunity to appear today.

I was unable to make a previously scheduled appearance before the Committee in July and I want to thank Representative Gradison, who chaired that hearing, for graciously allowing me to substitute one of our vice-presidents in my place.

I'm pleased to have this chance to share with the Commission the experience and perspective of organized labor on one of the historically key areas of union advocacy on behalf of our members -- health insurance coverage.

The labor movement has played a major role in developing the private insurance network that, through its coverage of some 65 percent of all Americans, is the backbone of health coverage in our country. But today, skyrocketing health care costs and declining access are fast destroying our employment-based insurance system.

It's common knowledge that of the 37 million Americans without insurance, two-thirds are full-time workers or dependents of these workers. Less well-known are the additional 40 to 50 million working Americans and their families who are finding medical benefits increasingly unaffordable.

Runaway health inflation is a prime culprit in this unraveling of employment-based health coverage. Employers' experiments with cost controls in the early 1980's has not done enough to slow healthcare inflation on an ongoing basis. Today, as health costs are rising faster than ever, employers are fast shifting the financial risks of health inflation to workers -- through higher out-of-pocket expenses -- and trying to eliminate health benefits altogether.

Health insurance has become too costly for most low-wage workers and their families, and even middle income families are now at risk for high medical bills. In 1987, individual expenditures for health care consumed 12.5 percent of disposable income, exceeded only by food and housing, and up from 9 percent a decade ago. At the current pace, spending for healthcare will equal that for housing within the next five years. These actions are threatening living standards and creating barriers to care for many working Americans.

And this erosion of employment-based benefits has been accompanied by draconian cutbacks in public programs that cover the nonworking population.

There's no relief in sight from these mounting cost pressures. Efforts to constrain expenditures by applying the breaks on one part of the health delivery system have simply caused spending to balloon elsewhere. If trends continue, healthcare expenditures could double by 1995 and triple by the turn of the century.

And these escalating health costs are not buying better quality services. According to the National Leadership Commission on Health Care "as much as 20 to 30 percent of all things done by well-meaning physicians in good hospitals is either inappropriate, ineffective, unnecessary and sometimes harmful."

Organized labor confronts this health "crisis" daily at the bargaining table. Bargaining affordable family health coverage for workers in low-wage industries has been an especially difficult task since the late seventies. But cost trends since 1986 are challenging the ability of union negotiators even to maintain affordable coverage established years ago for middle income workers and retirees.

Negotiators from the Communications Workers of America and the International Brotherhood of Electrical Workers recently concluded new collective bargaining agreements with AT&T and six regional phone companies where the key issue was what to do about health costs.

Despite years of joint union-management cost containment efforts, AT&T's health costs had topped one billion dollars a year, threatening the continuation of one of the largest single employer health plans in the nation.

Their settlement combined problem solving in the best tradition of collective bargaining with an historic commitment to work jointly for national health reform.

What they did amounted to a plea to get the question of health coverage off the bargaining table and into Congress.

Labor and management negotiators in the telecommunications industry are no different than their counterparts in other sectors of our economy.

They have implemented the cost containment measures recommended to them that were supposed to solve the problem and otherwise done what they could to preserve the health benefits of their workforce.

In the early 1980's, when we faced double digit increases in insurance premiums, employers responded with a variety of measures: devoting a larger share of their operating budgets to health insurance, instituting cost containment programs and shifting additional costs to workers -- forcing their employees to pay more out-of-pocket.

Where labor and management worked together to control costs instead of simply shifting the financial burden onto workers, a variety of innovative cost control programs were introduced, including mandatory second opinion surgery, hospital utilization review and a variety of managed care programs.

For a while, such cost containment initiatives seemed to have a tangible effect in holding down inflation in employer sponsored health plans.

But, after hesitating in 1985 and 1986, health insurance costs began rising faster than ever. In 1988, expenses were up 20 to 30 percent. And today insurers are asking for another 30 to 40 percent increase.

In 1989, unions and companies are facing a renewed challenge on health costs.

But now effective cost containment programs are harder to come by. Many employers have given up on attempting to control costs and are now simply interested in shifting the risk of health inflation to workers. Cost shifting disguised as cost containment is what's forcing workers in increasing numbers to put up picket lines.

The five-month strike between the United Mine Workers and Pittston Coal Group centers on the company's attempt to force workers into a new insurance plan that would require deductibles and sharply-increased coinsurance for family coverage. Under the Pittston plan, a miner and his family could actually end up paying five times more a year for health care. It is hard to overestimate the importance that health benefits hold for miners, who work in one of the nation's most dangerous occupations.

Across the country, management attempts to move health costs off their books onto workers' paychecks is the top strike threat. Just this week, in Washington, D.C. strikes over employer cost shifting were narrowly averted between Local 25 of the Hotel and Restaurant Workers Union and major downtown hotels and between Local 400 of the United Food and Commercial Workers Union and the Safeway and Giant food chains.

And a number of our unions -- including the United Rubber Workers, Machinists, Steelworkers, ACTWU, ICW, Brick and Glass -- are in negotiations with Armstrong Industries which already implemented health cutbacks for their non-union employees. The company plans the same for represented workers and also to eliminate the retiree health plan for all employees age 47 and younger. These employees are expected to pay for their retiree health benefits out of accounts established in a newly created ESOP.

Today, unions have all we can do just to hold on to what we negotiated in the past. In some industries, even that is no longer possible.

For earlier testimony before this Committee, we measured the trend of employer cost-shifting and the extent to which service sector workers are at risk for medical expenses by means of a survey of 178 plan options in 1987 and in 1989 covering roughly one-fifth of SEIU's 925,000 members.

The surveyed plans have several important characteristics:

First, most of the employees involved -- approximately 90 percent -- are in plans covering white-collar jobs in state and local governments with relatively good wage standards and benefit packages, including family health insurance. Currently, the average annual wage of these workers is over $28,000. Almost all the plans introduced extensive cost containment measures in the 1980's.

The remaining 10 percent of the workers surveyed are in plans covering low wage janitors, nurse aides, and office clericals where the average annual pay is $9,000 and health benefits are limited to basic services. Few cost control programs exist in these plans.

Second, nearly two-thirds of the 178 plan options surveyed were Health Maintenance Organizations (HMO's) or Preferred Provider Organizations (PPO's). The high penetration of HMO plans in the sample should mean that workers' out-of-pocket expenditures are lower than they otherwise would have been.

The study paints a bleak picture for the future of employment-based health insurance. Among the major findings:

First, health coverage obtained through private insurance for middle income workers is in grave danger due to a sudden, large jump in employee share of the cost of such coverage.

Worker premium contributions for family plans in our survey jumped 70 percent over the two years, double the average 35 percent rise in employer contributions.

Deductibles and copays followed suit, even though wages went up less than 10 percent in the same period.

As a result, middle income families in indemnity or PPO plans find themselves at risk for medical bills as high as 20 percent of after-tax income -- significantly above the level considered to be acceptable.

If current trends continue, these workers will be paying nearly $5,000 a year for routine care within the next five years.

Second, low wage service workers in the private sector are even worse off. Although technically insured, their coverage is unaffordable.

The study finds that more than a third of the disposable income of these workers would be required for premium contributions and deductibles alone -- expenses which must be paid before insurance coverage kicks in.

Total annual exposure for medical bills exceed after-tax income for the average worker in this category.

The survey results point out an important missing dimension in the health access debate: the erosion of private health insurance coverage isn't limited to the 37 million uninsured people in our country.

Millions more have employment-based coverage only on paper. Workers increasingly find their health benefits unaffordable as employers push an ever-larger share of the rapidly rising health costs onto their budgets.

These two trends -- more jobs without insurance and more jobs with unaffordable insurance -- are rapidly destroying the private insurance base of our country's health care system.

Unchecked health care inflation now threatens the living standard of American workers.

By taking more of the cost of health benefits out of workers' take-home pay, employers are further contributing to the declining standard of living.

Since 1987, payroll deductions for employment-based health care expenses, adjusted for inflation, rose 56 percent for family plans -- while real weekly earnings stagnated.

And real earnings have flattened in part because health care consumes a larger share of compensation. Since 1980, total health premiums grew an average 15 percent annually, while consumer prices rose at an average rate of 4.7 percent a year. If health premium increases had been held to the level of general inflation, the cost savings could have funded wage increases of 1.5 percent annually. That adds up to a potential 12 percent in lost wages over the last eight years.

Meanwhile, the sharply escalating cost of health care in the United States, relative to other countries, threatens our ability to compete in a global economy.

There is also a competitive disadvantage here at home for companies that provide health insurance and, in the process, pick up the tab -- estimated at 30 percent of recent premium increases -- for employers that refuse to provide health care benefits. In New Jersey, the building trades estimates that fifteen cents out of every dollar paid by its trust funds goes to subsidize health care for those contractors and other employers that don't provide health coverage.

The traditional employment-tied approach to providing health care in America is now widely considered to be inefficient, costly and unfair.

And unless we can restore equity and bring health costs under control, the employer-based insurance system will no longer be viable as our major vehicle of providing health coverage.

Yet, organized labor's experience at the bargaining table suggests that efforts at cost-control on an employer-by-employer basis is not capable of permanently slowing the rate of health care inflation.

Our recent study shows that cost-control measures implemented in the early 1980's lowered health costs below what they otherwise would have been, but weren't able to achieve ongoing savings.

Since 1987, health premiums in our sample plans have jumped an average 19 percent annually -- more than double the rate medical inflation (7 percent annually) and four times the increase in the Consumer Price Index (4.4 percent annually).

More can, and should, be done to control costs in employment-based insurance. We need to refine our cost containment tools and put a much greater emphasis on holding down the large volume of unnecessary, and often harmful, medical procedures which Americans are subjected to.

But we would seriously delude ourselves if we thought that additional cost-containment initiatives or new techniques such as managed-care had the potential to get at the underlying cost escalation.

The labor movement will continue to bargain aggressively to hold the line on health benefits, while working with management to achieve genuine cost savings. In this regard, the successful defense of health benefits by the Steelworkers, CWA, IBEW, the UAW, UFCW and Laborers -- and all our unions -- is so important.

But we recognize that it's not the long-run solution to our nation's health crisis.

That's because the root cause of our inability to rein in healthcare costs lies in the multiple financing mechanisms that characterize the U.S. delivery system. With thousands of public and private health plans, cost containment amounts to little more than each plan trying to shift costs elsewhere in the system.

Haggling with hospitals is a beggar-thy-neighbor game: a discount for one plan means higher charges for others.

Meanwhile, the federal government is busy shifting its' Medicare costs to retirees and employers. By bearing down on hospital costs, Medicare has now shifted much of the care for the elderly to the outpatient side, where seniors (or employers who offer retiree plans) are responsible for 20 percent of the bills.

In turn, employers saddled with skyrocketing costs and new corporate accounting rules that threaten their bottom-lines are looking to get out of the retiree health business altogether.

So they are shifting their rising costs to retirees through higher copays and fixed caps on their contributions, reducing coverage by requiring longer service to qualify, and ending benefits for future retirees. Next to cost-shifting for active employees, retiree health coverage is the thorniest issue -- especially for our industrial unions.

And, of course, employers without health coverage for their workforce are getting a "free ride" -- shifting their costs to everybody else.

It's a vicious cycle.

This deepening crisis in health care is forcing consumers, purchasers and even some providers to speak out on the need for change -- for a solution to the American health care dilemma. Unfortunately, there is no consensus yet on what these policies should be.

During the 1980's Congress has addressed access to health care in a piecemeal fashion. Looking ahead, the current tax and budget climate would seem to suggest that this approach will continue.

For its part, the labor movement will continue to support incremental efforts to expand Medicaid coverage and the "Minimum Health Benefits for All Americans Act," introduced by Senator Kennedy (D-MA) and Congressman Waxman (D-CA).

But we believe further action is needed both to control costs -- before the private insurance system totally unravels -- and to improve the quality and appropriateness of care.

We need a plan to move quickly to insure universal access, with effective cost control mechanisms, and new standards of quality assurance.

We need, in short, systemic reform carried out at the national level.

In recent months a host of comprehensive U.S. reform initiatives have surfaced: ranging from public-private partnership models, such as the National Leadership Commission on Health Care to a voucher-based system advocated by the Heritage Foundation; to Canadian-style national health insurance proposals from a physicians' group and the Committee for National Health Insurance.

These models all provide for universal access to care, but they differ to the degree in which they control costs and improve quality, and in their impact on employers, consumers, providers and insurers.

I urge the Commission to weigh all the reform proposals which are now being put forward and to bear in mind the lesson of labor's experience in recent years: that private insurance, arranged on a voluntary basis, is falling substantially short of the mark.

Recent polls indicate that the most popular choice -- because it's most familiar, if nothing else -- is to expand our mixed public-private system to provide access to all Americans. Since the uninsured are mainly lower income working Americans, the primary decision for policy-makers is whether to rely on public or private insurance as the main carrier for the low or moderate income working population. (Workers and their families make up nearly half of the more than 11 million uninsured under the poverty line.)

The direction taken has important budgetary considerations. Currently, a significant expansion in Medicaid eligibility alone would displace employer-provided coverage and add significantly to the federal budget deficit. Similarly, without Medicaid reform, employer mandates alone are problematic: unless copayments and deductibles are picked up by Medicaid, mandated minimum health benefits will result in high cost-sharing by low-income workers. Further, some Americans have no ties to the workforce.

In our view, if the nation goes this route a cooperative effort that builds on both the public and private insurance bases simultaneously is necessary to conserve scarce public dollars and insure that no one is left out of the system. It must also be accompanied by changes to reform the private insurance market and to put a lid on health expenditures at the state level by holding down doctors' fees, limiting unnecessary procedures and through all-payer systems or other approaches to increase the market power of buyers.

An alternate approach lies in a modified Canadian-style system, with government based financing and private delivery of care, which is best exemplified by the Health Security Partnership Plan put forward by the Committee for National Health Insurance.

In a recent Harris poll, 61 percent of Americans favored moving to a Canadian-type system. The appeal lies with Canada's combination of unqualified, universal access and the ability to control costs.

As the sole purchasers of health care, Canada's provincial governments wield considerable market power in negotiating with providers. Hospitals are given a "global" budget that is updated annually to reflect general inflation. The provinces negotiate budgets for physician services, and the effective fee schedules. Unlike the U.S., doctors are prohibited from charging patients more than the government will pay -- a practice known as "extra billing". The government also limits the availability of hospital beds, supply of physicians and the distribution of technology.

These controls have sharply curbed health inflation. Both the U.S. and Canada spent about 6 percent of GNP on health care in the mid-1960's when Canada's health program started. Since then, Canada's health care expenditures have grown only three points as a percent of GNP, while American expenditures doubled.

Unlike most other comprehensive reform models, the Health Security Partnership Plan, adapted to the uniquely American environment, stakes out a clear position on the need for tough cost control measures, along the lines of the Canadian approach.

The present moment requires strong Federal leadership to steer us out of the dangerous cross currents and to fashion a national plan to solve the triple problems of declining access, high costs and uncertain quality.

The call for national health reform is being echoed in many quarters. Now is the time to turn the growing consensus for national reform into a plan of action.

The Pepper Commission is in a unique position to break the policy logjam which has encumbered us these recent months. I know the Commission is equal to the task and you have our every best wish for success in your endeavors.

Thank you.

Chairman ROCKEFELLER. Thank you, John, very much.

Walter?

STATEMENT OF WALTER B. MAHER, DIRECTOR, FEDERAL RELATIONS FOR THE HUMAN RESOURCES OFFICE OF THE CHRYSLER MOTORS CORP.

Mr. MAHER. Thank you, Senator Rockefeller.

Chrysler appreciates having the opportunity to share with the Commission our concerns regarding the impact health costs have on the competitiveness of American business.

The uproar that Congress is presently hearing from the senior population regarding the Medicare Catastrophic Care Act is, in part, we believe, an expression of the same frustration that the business community and the labor movement is experiencing regarding how the cost of health care is eroding standards of living and sapping industrial strength and we hope that this Commission can help in the process of forging a solution to this most serious problem and we look forward to working with you in that effort.

The private sector has been hard at work at this problem for years. In mid-1981, Chrysler established America's first board of directors level committee devoted exclusively to analyzing Chrysler's health care cost problem and searching for solutions. Since that time, a substantial number of cost management initiatives have been adopted and even more actions are planned. But despite these actions, Chrysler has seen its per capita cost of providing health coverage to employees and retirees increase at an average annual rate of 8½ percent since 1981.

Now, while this was substantially better than the average business experience, it nevertheless represented a rate of increase which exceeded both CPI and GNP growth. Worse, the last 2 years have seen double-digit rates of increase.

In short, we and many other businesses have been running as fast as we can to combat the health care juggernaut and we're falling further and farther behind.

Americans spend about 40 percent more per capita on health care than the second most expensive country in the world, Canada, and we are well over 100 percent more expensive than Japan. We spend 90 percent more than West Germany, a country having a population much older than ours and which prides itself on its reliance on high-tech medicine and on its advanced research-oriented pharmaceutical industry.

Now, these statistics would not necessarily be so frightening if we're getting our money's worth. America, however, ranks but 16th in life expectancy, 17th in infant mortality. There's virtually no health professional who doesn't readily admit to the existence of wastefulness in the delivery and consumption of health services. And despite all of these expenditures, there's 37 million citizens without health coverage and you've heard ample testimony this morning about the other gaps in our system.

Let there be no doubt about it, any company in America offering health coverage to employees, if that company sells its products in competition with others produced abroad or it exports products and sells them abroad, that company is at a competitive disadvantage.

The U.S. company must effectively pay into a health system which requires from 40 percent to well over 100 percent more money to operate compared with health systems in other countries. Now, my company is concerned about the competitive damage inherent in those dramatic differences. We must compete with foreign automakers who have a $300 to $500 per car advantage over us due to health care costs alone.

Chairman **Rockefeller**. Is it true that the cost of steel costs less than the cost of health care at Chrysler?

Mr. **Maher**. Yes; the single largest vendor to Chrysler is the health care suppliers to Chrysler.

Now, Chrysler doesn't object to playing a role in financing our country's health system. All of our competitors, all of our international competitors in one way or another finance their country's systems. What we do object to is the fact that put in its broadest, macroeconomic perspective, America's health care system creates a type of export tax since many significant exports from the United States are produced by its largest companies which traditionally offer good employee health benefit plans. And given this perspective, the system actually contributes to the U.S. trade deficit and impairs competition on many levels.

Now, what's even more concerning is the fact that while our country is debating whether we really must engage in major system reform, much of the rest of the world is going to work to reduce their health costs. There is a serious move among the public and private sectors in Europe to develop strategies to make their health systems even more efficient. The Japanese are doing the same thing. Therefore, we run the risk in America of only exacerbating our problem if we do nothing and at best retaining the current huge competitive disadvantage if we elect simply to tinker in any solution.

We submit that fundamental change is required and in that respect it appears we have a lot of company. In a recent survey, 89 percent of Americans questioned expressed the need for substantial health system reform and no wonder, business pays only about 25 percent of America's health care bill. Federal, State, and local government programs pay 40 percent of the tab, using citizen tax dollars, of course, and individuals pay about one-third, the bulk of the balance, either through direct patient payments or private insurance premiums. This represents a painfully high, yet quite subtle surtax on all Americans in dollar amounts which grow every year forcing lifestyle tradeoffs and, more often than not, eroding living standards.

Now, the causes of the problem are legion, but a factor undoubtedly contributing to most of this, is that America's healthy system per se has never had to cope with any semblance of a resource limit. Further, health care has not appeared to be the type of good or service where purchasers, at least up to now, have been able to step in and regain overall control.

So, is change necessary or is there some magic solution about to appear as a result of all the work done during the past decade by the public and private sectors in searching for a solution? I fear not. Over the past three decades, with the sole exception of the 2 oil shock years, health care has outstripped CPI growth. If anything, the gap has widened during the alleged era of cost containment.

Looking ahead, what do we see? We see that the—we face these real facts. The elderly consumer requires more health services than the nonelderly. The elderly as a percent of the total population is growing. If health care inflation is permitted to continue at two or more times the rate of CPI growth, health care mathematically will slowly consume the GNP.

In fact, if health care grows only at the rate of inflation, the CPI growth, it will consume more and more of the GNP as the elderly grow in number, forcing more societal tradeoffs.

Now it appears to us that, given these frankly inescapable facts and the fact that we are so uncompetitive now, that tinkering around the edges of our system will not suffice. If we examine the health systems other countries have adopted, while they vary widely, we find two common denominators. They provide protection for all their citizens, and they have effectively established a process which provides some measure of control over how much of a country's resources its health system can consume. Now while the U.S. health care system has many, many wonderful attributes, these two features are missing. And I submit that we can embrace them without detracting from the good our system has to offer.

For example, recent recommendations to Congress, which you are aware of, Senator Rockefeller, by the Physician Payment Review Commission, a group established to advise Congress on reforms in Medicare policies for paying physicians, point toward a direction we believe requires your serious consideration for total system reform, particularly the recommendation that to control year over year growth in spending for physician services, annual expenditure targets be established and subsequent year's rate of fee increases take into account overall compliance with the target. We submit that in the absence of effective practice guidelines, this is a particularly appropriate recommendation.

Now some will argue that setting expenditure targets, in other words requiring the Nation's health system to discharge its responsibilities while living within some semblance of a budget like all other segments of our society must do, will cause a rationing of health services in America.

First, we should not fear rationing excess. Instead, we should seek to eliminate it.

Second, we should not entertain such arguments until the medical experts who are regularly reporting on the high volume of unnecessary and ineffective medical care rendered in this country report that that problem has disappeared.

In conclusion, as the Commission continues its deliberation and focuses on solutions, we ask you pay particular attention to how that solution impacts our Nation's competitiveness. If your recommendations presume a continued role by business in financing the health system, you must consider how that role will affect the cost of production here in America and the resulting impact on international competitiveness.

If the data you have tell you that the result will be that competitiveness suffers, we urge you to reject any solution which produces that result. For just as the public ultimately pays the price for our health care system in the form of increased doctor bills, increased insurance premiums, increased taxes, lower wages, higher prices of goods and services, reduced standard of living, it also is at a risk of paying the price by losing a job because their employers business failed in whole or in part due to the unconscionably high cost of health care in America.

We wish you the best of luck with your efforts, and we stand ready to be of any assistance that we can to you or your staff.

[The prepared statement of Mr. Maher follows:]

Statement by Walter B. Maher, Director - Federal Relations, Human Resources Office, Chrysler Motors Corporation, Before The Pepper Commission on Long-Term Care and Access to Health Care: Examining the Scope of the Problems, Washington, DC, September 21, 1989

Chrysler Corporation appreciates having the opportunity to share with this Commission our concerns regarding the impact health costs have on the competitiveness of American business.

The uproar Congress is presently hearing from the senior population regarding the Medicare Catastrophic Care Act is, in part, an expression of the same frustration felt by the business community and the labor movement regarding how the cost of health care is eroding standards of living and sapping industrial strength.

We hope this Commission can help in the process of forging a solution to this most serious problem.

Initially we trust you will conclude that there is, indeed, a problem, that it is one of massive proportion, and that it requires scrutiny of the financial incentives present in our system which are a byproduct of the way we have elected to pay for health care in America.

The private sector has been hard at work on this problem for years. In mid-1981, Chrysler established America's first Board of Directors'-level committee devoted exclusively to analyzing Chrysler's health care cost problem and searching for solutions. Since that time, a substantial number of cost management initiatives have been adopted and even more actions are planned. Despite these actions, Chrysler has seen its per capita cost of providing health coverage to employees and retirees increase at an average annual rate of 8.5 percent since 1981. While this was substantially better than the average business' experience, it nevertheless represented a rate of increase which exceeded both CPI and GNP growth. Worse, the last two years have seen double-digit rates of increase. In short, we and many other businesses have been running as fast as we can to combat the health care juggernaut, and we are falling farther and farther behind.

As a result, late last year we stepped back and asked ourselves: we have been analyzing and working on this issue for 8 years; what have we learned? This is what we have learned:

- U.S. health costs are the highest in the world by far.
- The high rate of expenditures is not yielding better health care for all Americans.
- There is a substantial amount of dissatisfaction with the system, both from payers and from millions of uninsured Americans.
- A business adopting sound health cost management strategies can achieve significantly lower costs.

. Even the costs of a well-organized program are excessive and render U.S. business non-competitive in world markets.

Americans spend about 40 percent more per capita on health care than the second most expensive country in the world (Canada); and we are well over 100 percent more expensive than Japan. We spend almost 90 percent more than West Germany, a country having a population much older than ours and which prides itself on its reliance on high-tech medicine and on its advanced, research-oriented pharmaceutical industry. These statistics would not necessarily be so frightening if we were getting our money's worth. America, however, ranks but 16th in life expectancy and 17th in infant mortality; there is virtually no health professional who does not readily admit to the existence of wastefulness in the delivery and consumption of health services; and despite all these expenditures, there are 37 million U.S. citizens without health coverage.

Let there be no doubt about it, any company in America offering health coverage to employees, if that company sells its products in competition with others produced abroad, or exports products and sells them abroad, is at a competitive disadvantage. The U.S. company must effectively pay into a health system which requires from 40 percent to well over 100 percent more money to operate compared with health systems in other countries.

My company is concerned about the competitive damage inherent in these dramatic differences. We must compete with foreign automakers who have a $300 to $500 per car advantage over us due to health care costs alone. Coming off 1988, which saw business health costs in general increase a reported 22 percent, Hewitt Associates, a leading employee benefits consulting firm, has forecasted 1989 costs will increase another 21.5 percent. American business clearly cannot continue funding such a health care system and succeed against international competitors. Chrysler does not object to playing a role in financing our country's health system. All of our international competitors, in one way or other, finance their countries' systems. What we do object to is the fact that, put in its broadest, macroeconomic perspective, America's health care system creates a type of export tax since many significant exports from the U.S. are produced by its largest companies which traditionally offer good employee health benefit plans. Given this perspective, the system actually contributes to the U.S. trade deficit and impairs competition on many levels.

What is even more concerning is the fact that, while our country is debating whether we really must engage in major system reform, much of the rest of the world is going to work to reduce their health costs. There is a serious move among the public and private sectors in Europe to develop strategies to make their health systems even more efficient. The Japanese are doing the same thing. Therefore, we run the risk in America of only exacerbating our problem if we do nothing and, at best, retaining the current huge competitive disadvantage if we simply tinker.

We submit that fundamental change is required. In that respect it appears we have a lot of company. In a recent survey 89 percent of Americans questioned expressed a need for substantial health system reform. And no wonder. Business pays only about 25 percent of America's health care bill. Federal, state, and local government programs pay 40 percent of the tab (using citizen tax dollars, of course); and individuals pay 33 percent, the bulk of the balance, either through direct patient payments or private insurance premiums. This represents a painfully high, yet quite subtle, surtax on all Americans, in dollar amounts which grow every year forcing lifestyle tradeoffs and, more often than not, eroding living standards.

And for what?

- 40 percent unused capacity in American hospitals.
- Two, three and four times the number of C-section deliveries than are medically necessary.
- 14 percent inappropriate and 30 percent questionable bypass surgeries.
- etc., etc., etc.

The causes of this problem are legion, but a factor undoubtedly contributing to most of them is that America's health system per se has never had to cope with any semblance of a resource limit. Further, health care has not appeared to be the type of good or service where purchasers, at least up to now, have been able to step in and regain overall control. As a result, based on analyses of both Medicare and private sector health benefit utilization, we have a system which encourages the provision of a high volume of unnecessary or questionable medical services, we observe significant variations in physician practice patterns with no difference in patient outcome, and new technology is substantially overused; (most of the above receives a powerful stimulus from the malpractice crisis that envelops medicine).

Is change necessary? Is there some magic solution about to appear as a result of all the work done during the past decade by the public and private sectors in searching for a solution? I fear not. Over the past three decades, with the sole exception of the two oil shock years, health care has outstripped CPI growth. If anything the gap has widened during the alleged era of cost containment. Looking ahead we face these real facts:

. The elderly consume more health services than the non-elderly.

. The elderly, as a percentage of the total population, is growing.

. If health care inflation is permitted to continue at two or more times the rate of CPI growth, health care will slowly consume the GNP.

. In fact, if health care is permitted even to increase at the rate of CPI growth, it will consume more and more of the GNP as the elderly grow in number, forcing more societal tradeoffs.

It appears to us that, given these inescapable facts and the fact that we are so uncompetitive now, tinkering around the edges of our system will not suffice.

If we examine the health systems other countries have adopted, while they vary widely we find two common denominators: they provide protection for all their citizens, and they have effectively established a process which provides some measure of control over how much of a country's resources its health system can consume. While the U.S. health care system has many, many wonderful attributes, these two features are missing. I submit we can embrace them without detracting from the good our system has to offer.

Recent recommendations to Congress by the Physician Payment Review Commission, a group established to advise Congress on reforms in Medicare policies for paying physicians, point towards a direction we believe requires your serious consideration for total system reform:

. To rationalize the current pattern of payments among physicians, which has overpriced and promoted an inappropriate volume of many surgical and technical procedures and undercompensated evaluation services, the Commission proposed to revise the Medicare fee schedule to base payments primarily on the resource costs incurred in efficient medical practice.

. To help assure the delivery of quality, effective health care, the

Commission proposed funding should be provided to support effectiveness research and practice guidelines. The development of practice guidelines may not only serve to reduce unnecessary services and improve quality but may also provide protection from malpractice liability for physicians who follow them.

. To control year-over-year growth in spending for physicians' services annual expenditure targets are proposed and subsequent year's rate of fee increase would take into account overall compliance with the target. In the absence of effective practice guidelines, we believe this is a particularly appropriate recommendation.

Some will argue that setting expenditure targets (in other words, requiring the nation's health system to discharge it responsibilities while living within some semblance of a budget, like all other segments of our society must do) will cause a rationing of health services in America. First, we should not fear rationing excess; instead we should seek to eliminate it. Second, we should not entertain such arguments until the medical experts who are regularly reporting on the high volume of unnecessary and ineffective medical care rendered in this country report that that problem has disappeared.

In conclusion, as the Commission continues its deliberation and focuses on solutions, we ask you pay particular attention to how that solution impacts our nation's competitiveness. If your recommendations presume a continued role by business in financing the health system, you must consider how that role will affect the cost of production here in America and the resulting impact on international competitiveness. If the data you have tell you that the result will be competitiveness suffers, we urge you to reject any solution which produces that result. For just as the public ultimately pays the price for our health care system in the form of increased doctor bills, increased insurance premiums, increased taxes, lower wages, higher prices of goods and services, and reduced standard of living, it also is at risk of paying the price by losing a job because their employer's business failed due in whole or in part to the unconsciously high cost of health care in America.

We wish you success and stand ready to offer whatever assistance you or your staff may require.

Chairman **Rockefeller**. Walter and the departed John and Peggy, thank you very, very much. I'm going to ask for your indulgence and ask my fellow Commission members for their indulgence in that we are about 1 hour behind schedule now. I want to be able to move on to the next panel, unless either of the Commissioners has something that they just very much want to ask.

Representative **Oakar**. Mr. Chairman, this is the panel that I did have a few questions of, but if you want to proceed, I guess we could. I'll ask them in writing. But I think the message of corporate and the labor movement, Mr. Chairman, sort of acting in sync for a change or on occasion in terms of philosophy is very, very important. But whatever the Chair's wishes are are terrific.

Chairman **Rockefeller**. I appreciate both of you, your indulgence not only of not having to answer questions, but for being here in the first place.

I would call now to the witness table, Robert Blendon, from the Harvard School of Public Health and also Carroll Estes, from the University of California at San Francisco, Aging Health Policy Center.

Mr. Blendon will talk on—reflecting on what each of these folks have heard this morning so far, Mr. Blendon will talk about the coverage and the cost and the quality in the matter of health insurance, and Ms. Estes will talk about the long-term care problem, reflecting on part of what they've heard and some of their own thoughts in terms of need, coverage, and insurability. And you may have other things you want to say too.

So Mr. Blendon, I might start off with you, sir.

STATEMENT OF ROBERT J. BLENDON, SC.D., HARVARD UNIVERSITY SCHOOL OF PUBLIC HEALTH

Mr. **Blendon**. Bob Blendon.

Senator Pryor and Congressman Gradison gave my testimony this morning. That is, they presented the basic facts of the problem. So, what I want to do is highlight very quickly for you a couple of the issues that were in the testimony, and one piece of history, if you will allow me.

In 1974, both Houses of Congress were considering this problem and had, simultaneously, 15 bills before them. At that time, it may be hard to believe, Richard Nixon was sponsoring something called mandated health insurance as the Republican alternative. He got the idea from this fellow named Nelson Rockefeller, who was then Governor of New York, who had proposed it in the State of New York. On the other side, Senator Kennedy was proposing a Canada-like plan for the United States, and Wilbur Mills' position was in between.

On the last day of the testimony, five people testified and said the following:

First, Federal Government is going to mess this problem up. Leave it to the private sector, doctors, and hospitals.

Second, hospitals are the safety net in this country. Hospitals will take care of the people who see them and need them, and all the Federal Government will do is just remove the hospital responsibility.

What I want to summarize for you is 14 years of research since the lights went off, the meeting went out, and everybody turned and said: "Let's leave it to the docs, the hospitals, and the private sector."

First, we've had a 25-percent increase in the number of people in the United States without health insurance, and 50 percent in the State of California. Now a point which gets blurred over in every testimony by an official; that is, we are not just talking about the poor, but the working poor. It turns out that 80 percent of the uninsured people are in working families; 70 percent have incomes that are above poverty. What's happening is that we are basically having our private health insurance system fall apart, and working people that used to have the insurance when they were holding those hearings in 1974 don't have it anymore.

Second, let me deal with the hospital issue. We have so much research, and the Congress has been incredibly generous to the research community to look at who doesn't get care in America. So let me summarize 14 years for you. If I rolled the research results in, the pile would be above the Senator's head.

Basically, there is a group of uninsured that gets into the system and the hospitals do something for them. There's a very substantial group that do not. Of 100 kids without insurance, and 100 kids with insurance; the uninsured report 35 percent less use of a doctor. Of people who say they're sick and have no insurance, versus people who are sick and say they have insurance; 40 percent more of the latter group have access to a doctor.

Now when I testified years ago, a writer for the Wall Street Journal looked me in the eyes and said: "Bob, the people without insurance don't need it. Let's face it. They're not sick. They just hang around hospital outpatient departments."

So with the Rand Corp., we developed a study where 100 doctors listed a set of symptoms which they believed absolutely had to be seen by a doctor. The symptoms include pain in chest during light exercise, unexplained bleeding, fainting all the time, losing weight when you're not on a diet. It's not difficult to agree, I expect, that people with these problems should see a doctor.

The results of two national studies say as follows. The majority of Americans with insurance who have those symptoms see a doctor. The majority of Americans with these same symptoms, such as pain in the chest, don't see a doctor. So it isn't a matter of just languishing around the outpatient department.

The next argument was, basically, the sick ones always get to the hospital and we take care of them. It turns out that the New England Journal, in the last 4 years, has been filled with matched studies of people with insurance/without insurance, such as low birth weight infants and people who've been dropped from Medicaid with chronic illnesses. The insured turn out worse.

So now, what the research community can say to you is, guess what, it's a working people's problem. It's getting worse. The uninsured don't get the care. The hospitals don't pick them all up. And I think you heard it this morning. So, that's point No. 1.

Point No. 2 is the fact that we know from an incredible amount of research that insurance cures this problem. Now you'll go on forever about 12 plans. But I am the guilty one that had the nerve, with Lou Harris, to ask Americans if they'd rather have Canada, and ask Canadians if they'd rather have America. And there was a finding in that study that, because it was researchy, nobody talks about.

We took the Newsweek cover—got it?—the front page of Newsweek, and we asked Canadians and Americans as this cover did: "Do you think that you can afford to get sick?" We asked them last year. We said: "Is there a time when you were sick and you may have needed medical care and you could not get it for financial reasons?"—7½ percent of Americans said: "Yes, last year I was sick. I couldn't get the care for financial reasons."

The same telephone caller to Canadians was told that they didn't know what we were talking about, only 0.5 percent of people in Canada said they couldn't get care for financial reasons. They thought we were speaking in a foreign language. They did not know. In just an hour and a half flight from here you could not sell the same Newsweek front cover.

So the point I want to make isn't that you need a Canadian approach, though it's one alternative. It is that the scientific community has to tell you insurance works. When people have it, you don't have the kind of testimonies you heard this morning.

Now let me fill in just a few of the numbers around the testimonies. It goes like this.

Basically, 21 percent of Americans say: "I don't have enough money or insurance to care for myself if I get sick."

Last year 7½ percent (representing nearly 14 million people) actually got sick and tried it out.

A million of them turn out to have Pam Young's experience. That is, they march out to their doctors and hospitals, the ones who are volunteering to give all the care, who are there 24 hours a day to give it away free, and they discover that they're sent home and they're told flat out that the reason that they are sent home is financial.

That's the epidemiology of the U.S. problem. It is curable by insurance.

Now I am going to finish with just two points.

One is, if you go back over the last year, the majority of the testimony before these committees continually talks about this problem as one of the poor, working poor. I have a paper that just came out which shows that public interest in national health insurance has gone up by 20 percent—I analyze health polls in the other part of my life—since 1982. The real support is all among working people.

And what we are offering them is a welfare program. We get in there and say: "Let's muck up Medicaid some way." You're primarily talking about people who didn't know they were indigent until they had $150,000 heart valve operation for their child. And we're telling them how nifty welfare will be for them.

If you didn't like catastrophic and the political reaction, let me tell you that to send the majority of people who are working down to the welfare office as the cure for the problem they think they should be able to solve where they work is a political disaster.

The second point is a personal observation. When I testified before the Missouri State Legislature, they were convinced that we had a problem. They had no argument after the testimony was over. But they looked me in the eyes and they said: "Bob, let me give it to you straight out. We can't afford to do anything about this, because of the Koreans. Basically, we've got to compete with Taiwan. We've got to compete with Korea. We've got to compete with Japan. We can't afford to cover this."

Let me tell you that the Koreans went out and they took Nelson Rockefeller's plan. They have mandated every single sushi bar, every single clothing place, every small business. Today, 100 percent of Korea has mandated insurance. Japan has covered every single person. And when I talked to the Japanese Minister of Health and said: "Why don't you let the small businesses out and drop insurance?" they said: "Nobody in our political leadership would allow the Japanese to compete with the Americans by dropping insurance coverage." So ours is the only country that manages to enter the marketplace and not take this issue off the bargaining table.

Thank you.

[The background material presented by Mr. Blendon follows:]

Access to Care and the Uninsured

Background material from Robert J. Blendon, Sc.D.,
Harvard University School of Public Health, for the
Pepper Commission on Comprehensive Health Care
U.S. House of Representatives
Washington D.C.

September, 1989

SUMMARY

1. Most Americans who have health insurance report few difficulties in obtaining access to health care;

2. However, Americans who do not have health insurance report major barriers to obtaining needed medical care.

3. America's "safety net" for those who are uninsured appears to be unravelling.

4. Americans are deeply concerned the about problems in our health care system and say they want a fundamental change in the direction of the system.

5. There is strong support for new federal initiatives in health care, including mandatory employer provided health insurance benefits, and even a change as dramatic as adopting a national health insurance system like the one in Canada.

Health care in 1989 is vastly different than it was a decade ago. An aging population, the escalating AIDS epidemic, a looming physician surplus and continuing nursing shortage, the emergence of large multi-hospital corporations, the growth of health maintenance organizations, the commercialization of medicine, new systems for paying our hospitals, technological advances, a plethora of new outpatient treatment facilities, and failed cost containment strategies are forcing changes in our health care system.

Over the coming decade, the Congress will increasingly be confronted by the polarized positions of one set of constituents who see the many changes in our system leading to dramatic improvements in our ability to provide health care services and another which predicts pending national disaster. It is clear that these conflicts will not be easily resolved.

Two questions are commonly asked in this changing environment: 1) Do all Americans have access to needed health care regardless of their ability to pay? Surveys show that Americans are almost unanimous (82%) in their support for the principle that health services should be available to all citizens,[1] and 2) What do Americans think about the problems and future of our health care system?

In this background paper, I will attempt to answer these questions briefly and simply. In this discussion, I rely on a number of data sources but most importantly on the UCLA-Robert Wood Johnson national survey of Access to Health Care and on two recent publications, including the results of a School of Public Health/Louis Harris survey of American, Canadian and British citizens, and a review of surveys on health as a national priority.[2,3,4,5] My conclusions are as follows:

1. Most Americans who have health insurance report few difficulties in obtaining access to health care. Nearly nine out of ten insured persons say that they did not have problems in obtaining the medical or surgical care they needed. A similar proportion report they had a regular source of medical care, be it a physician, hospital, HMO, etc., and they were satisfied with their last experience with it.[1,2,3]

2. However, Americans without health insurance report major barriers to obtaining needed medical care. Even though our country's hospitals now provide nearly ten billion dollars a year of uncompensated care, national studies continue to show a wide disparity between the ability of the uninsured and the insured to obtain health services.[2,3,4] The UCLA - Robert Wood Johnson study describes this worrisome situation. As shown in Exhibits 1 and 2, people under the age of sixty-five without health insurance, although generally less healthy than their insured counterparts, saw physicians 27% less frequently and were hospitalized 19% less often. Similarly, this figure was 34% less for visits to physicians by uninsured children. In addition, the study found the general gap in receipt of physician care was widest for those who were in the most ill health (Exhibit 3). Those uninsured who described themselves as being in fair or poor health reported 40% fewer visits to a doctor than those with health insurance. Similar results are found in a recent report by the Congressional Research Service and are shown in Exhibits 4 and 5.[6]

Twenty-one percent of Americans reported in a recent Gallup poll that, in the past year, they did not have enough money to pay for their health care needs. This figure has risen from 15 percent in 1974 (Exhibit 6).[5] Other studies indicate that 6% of Americans (an estimated 13.5 million people) said they were actually unable to obtain needed medical care because they did not have adequate financial resources. An estimated one million Americans people reported that they tried to obtain needed medical care but were refused by doctors or hospitals for financial reasons.[2,3] The 1986 figure was confirmed in 1988 -- 7.5% of Americans responding to the Harvard/Harris study said they were unable to get medical care for financial reasons.[3] The majority of Americans experiencing these difficulties were uninsured or poor. As a point of comparison, Canadians, when asked the identical question, report only .6% of their population having this problem. The Robert Wood Johnson survey the survey indicates that people without health insurance saw physicians 50% less often for symptoms of serious illness than those who were insured. The symptoms, judged by a panel of physicians to warrant seeing a doctor, included unexplained bleeding, periodic loss of consciousness or fainting, and chest pain when exercising.[2,3,4]

The large proportion of pregnant women who did not seek prenatal care in the first three months of their pregnancy is especially troubling. A recent Institute of Medicine study concluded that early prenatal care leads to improved maternal and infant outcomes.[8] However, although infant mortality in the United States has been reduced by half since 1970, the rates of infant death in this country still exceed those of many other comparable industrialized countries.[9] It is therefore of concern to find one in five uninsured pregnant women surveyed in 1986 did not seek medical care early in their pregnancies (Exhibit 7).[2,3]

These studies suggest that as a result of Medicare and Medicaid, to be poor in America is no longer a major deterrent to obtaining adequate health care.[10,11] But to be uninsured is! To be both uninsured and poor remains the most serious problem of all.

3. America's "safety net" for those who are uninsured appears to be unravelling. Over the years, the United States has gradually adopted a three-track system of health care financing. The first track has been private health insurance for employees and their families. The second is public insurance for the poor on welfare rolls, the disabled, and

the retired. The third is a system of governmentally subsidized public hospitals and neighborhood health centers, coupled with a major commitment of more than six thousand philanthropically supported non-profit hospitals, that provide free or subsidized care to the poor who are not on welfare or to the uninsured. This three-track system appears to be breaking down. A number of forces are at work here:

- Private sector concerns with economic conditions and competitiveness have led since 1980 to a 25% increase in the proportion of Americans without health insurance. Thus we see nearly two-thirds of the 37 million uninsured (62%) are in families with an adult currently holding a job, but without health insurance coverage.[6]

- Fiscal pressures on federal and state governments have resulted in a decline since 1975 in the proportion of the nation's poor and near-poor covered by Medicaid (Exhibit 8).[12,13]

- Real growth in philanthropic spending in health care has declined from 4.6% of national health expenditures in 1970 to 2.7% today. Real private giving is now a smaller source of revenues for the charity care offered by non-profit voluntary institutions.[14,15]

- The amount of "free care" provided by voluntary hospitals is not sufficient to meet the growing proportion of uninsured in the communities they serve. Communities that have no municipal hospital are encountering additional difficulties. Today one-third of the nation's hundred largest cities have no public free care institution and the poor must depend on non-profit hospitals for uncompensated care.[1]

- One of the indirect mechanisms by which the nation has financed care for the poor is rapidly changing. Historically, middle-class Americans have overpaid for their health care services, and these overpayments have subsidized care for the poor. However, in the face of rising health care costs, many private business and union health insurance policies prohibit the shift of the costs of medical care for the poor to their members policies. This phenomenon has been encouraged indirectly by the ERISA pension legislation.

These trends, when viewed together, suggest that the question of who will pay for the care of the uninsured is becoming a critical health care issue for the nation.

4. Americans are deeply concerned about our health care system. The overwhelming majority (80%) of Americans say they want a fundamental change in our health care system. This level of frustration and concern is so high that there is a demand for new initiatives to solve the problem. Gallup and Harris surveys have indicated that public support for additional federal expenditures for health care is second only to support for education, and 71% of Americans think the U.S. is not spending enough on health care.[5]

5. The public strongly supports the idea that the federal government should take the lead in planning a new direction for U.S. health policy. The most popular option is mandating employer provided health insurance, a proposal that is supported by 74% of the public. 61% go so far as to say that they would prefer a national health insurance system such as that in place in Canada to the status quo in the U.S. (Exhibit 9). Similar findings were seen in a 1989 survey in which 67% of Americans said theyfavored

a national health plan that is totally government financed, a response that has risen from 42% since 1982 (Exhibit 10).[2,3,5]

The Congress and the President face an historic opportunity to act in this moment of national discontent by proposing the enactment of a federally sponsored universal health insurance program. To capture the public's imagination, this proposal need not look like Canada's health system. It could include the involvement of pluralism, state government, and the private insurance industry. Affording some citizens the opportunity to buy into an already stressed and inconsistently implemented Medicaid program will not be sufficient. The plan must guarantee basic health insurance coverage to every American, and place government in a central role in containing health costs, not just for Medicare, but for the nation as a whole. In this area Americans clearly want government's help. The public sees itself as helpless in confronting rising physician's fees, hospital charges, and the possibility of receiving inadequate health care.

REFERENCES

1. Freeman, HE, RJ Blendon, LH Alken, S Sudman, CF Mullinix, CR Corey. Americans Report on Their Access to Care. Health Affairs. Spring 1987.

2. Freeman, HE. Americans Report on their Health Care -- A Fact Book. CA:UCLA Report, May, 1987.

3. The Robert Wood Johnson Foundation. Access to Health Care in the United States: Results of a 1986 Survey. Special Report, Princeton, NJ. Number 2, 1987.

4. Blendon, RJ. Three Systems: A Comparative Survey. Health Management Quarterly. 10(1) 1989.

5. Blendon, RJ, K Donelan. The 1988 Election: How Important Was Health? Health Affairs, Fall 1989; in press.

6. Congressional Research Service. Health Insurance and the Uninsured: Background Data and Analysis. Education and Labor Serial 100-Z. U.S. Government Printing Office, May 1988.

7. Institute of Medicine. Preventing Low Birthweight. Washington, D.C.: U.S. Government Printing Office, March 1988.

8. National Center for Health Statistics. Health United States 1987. DHHS Pub. No. (PHS) 88-1232. Washington D.C.: U.S> Government Printing Office, March 1988.

9. Rogers, DE, RJ Blendon, TW Moloney. Who Needs Medicaid? New England Journal of Medicine, 307: 13-18, 1982.

10. Blendon RJ. The Problems of Cost, Access, and Distribution of Medical Care. Daedalus 115(2): 119-135, 1986.

11. Unpublished data, Division of Medicaid Statistics, Health Care Financing Administration, 1988, 1989.

12. U.S. Bureau of Census. Current Population Reports, Series P-60.

13. AAFRC Trust for Philanthropy. Giving USA. New York: AAFRC, 1987.

14. Health Care Financing Administration National Health Expenditures, 1986-2000. Health Care Financing Review 8(4): 1-36, Summer, 1987.

EXHIBITS 1-9

EXHIBIT 1

Mean Number of Physician Visits, Percent Hospitalized, And Perceived Health Status By Insurance Coverage For Persons Under 65

Insurance coverage	Physician Visits	Percent in fair/poor health
Uninsured	3.2	12%
Insured	4.4	9
Gap (percent)	-27%	
	Percent hospitalized	
Uninsured	4.6	12
Insured	5.7	9
Gap (percent)	-19%	

EXHIBIT 2

Mean Number of Physician Visits By Insurance Coverage For Children Under 17

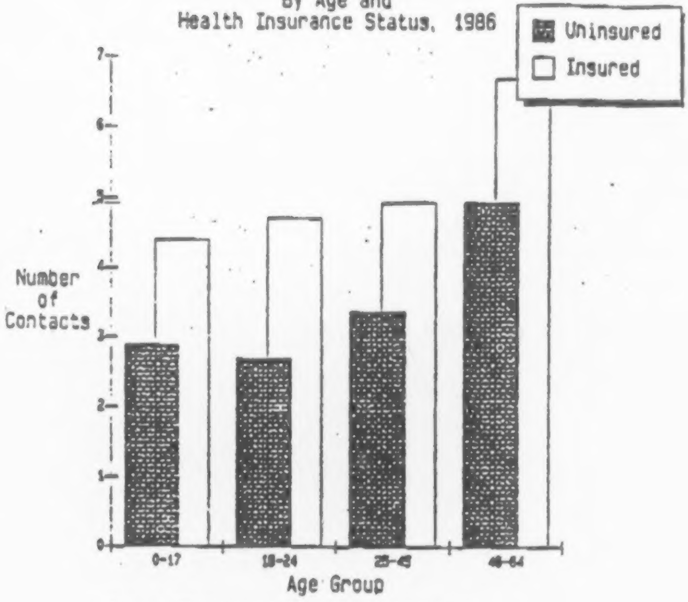
Insurance coverage	Physician Visits	Percent in fair/poor health
Uninsured Children	2.5	6.4%
Insured Children	3.8	6
Gap (percent)	-34%	

EXHIBIT 3

Mean Numbers of Physician Visits For Those Under The Age of 65 in Fair or Poor Health

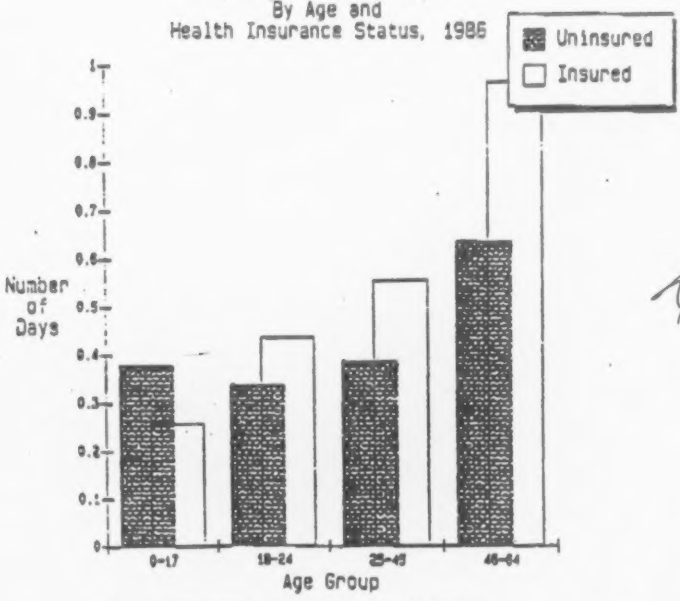
Insurance Coverage	Physician Visits
Uninsured	6
Insured	10
Gap (percent)	-40%

Exhibit 4
Average Physician Contacts
By Age and
Health Insurance Status, 1986



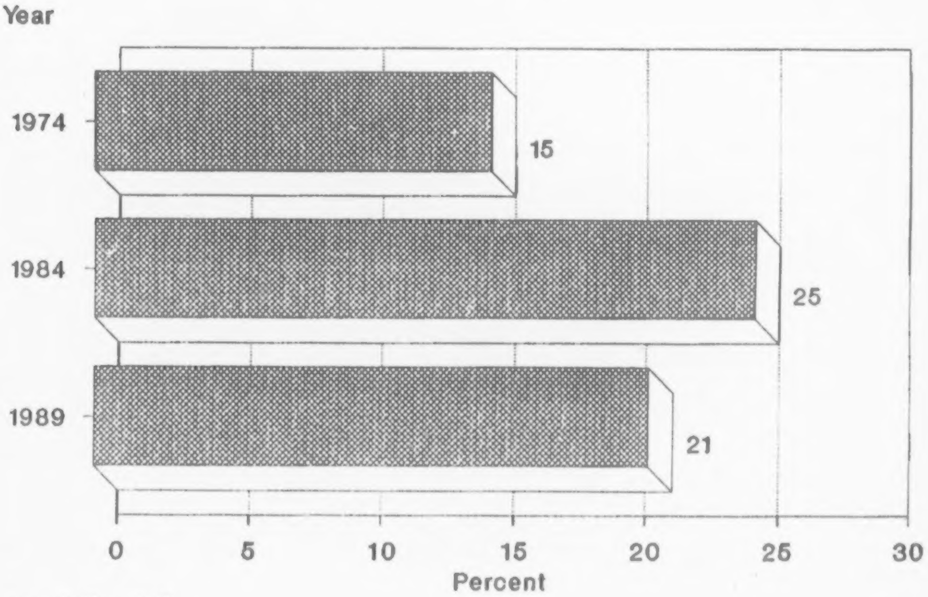
Source: CRS analysis of 1986 HIS public use tapes.

Exhibit 5
Average Hospital Days
By Age and
Health Insurance Status, 1986



Source: CRS analysis of 1986 HIS public use tapes.

Americans Reporting Not Enough Money for Health Care in Past Year



Source: Gallup Poll

▨ TOTAL U.S.C.
☐ UNINSURED

EXHIBIT 7

Indicators Of Potential Underuse Of Medical Care

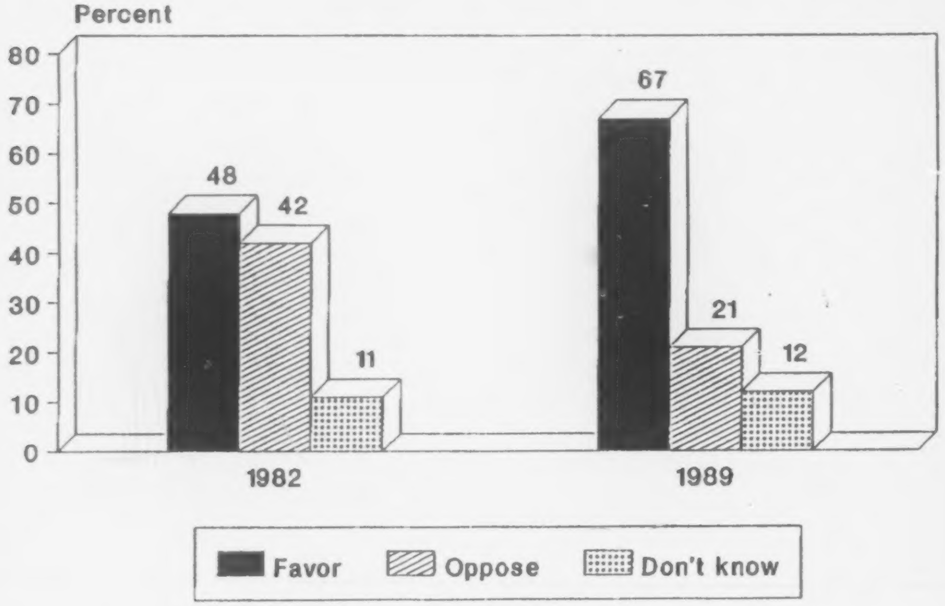
Problem	U.S. Total	Uninsured
Percent with chronic illness without physician visit in a year	17%	20%
Among persons with one or more physician visits in year, percent with serious symptoms who did not see or contact a physician.	41	67
Percent pregnant women without first trimester prenatal care	15	20
Percent of Americans not receiving care for financial reasons (1986)	6	20
Percent of Americans not receiving care for financial reasons (1988)	7.5	24

EXHIBIT 8

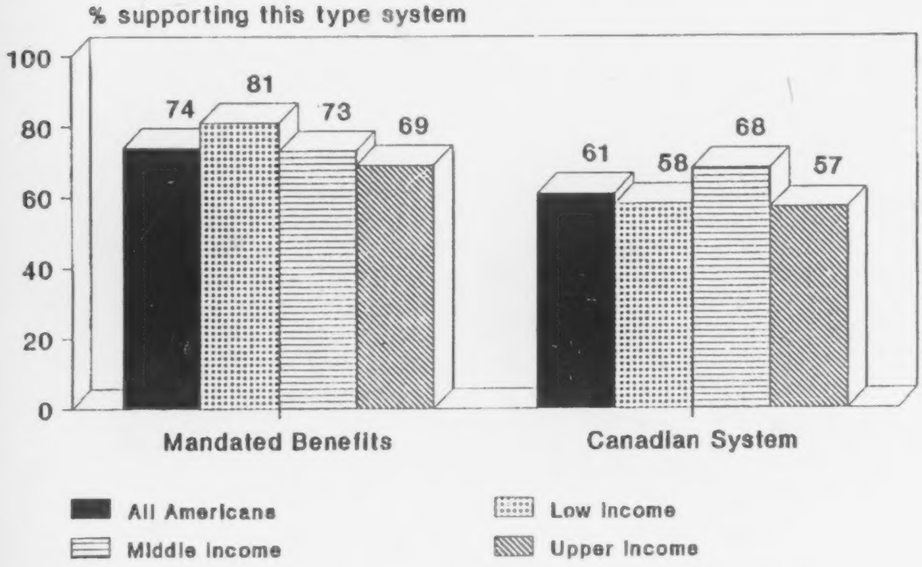
Medicaid Recipients as a Percentage of Persons Below 125% of Poverty, 1972-87

1972	45%
1975	59%
1980	53%
1985	49%
1987	53%

Support for a National Health Plan That is Totally Government Financed



Sources: New York Times, NBC News



Mandated Benefits vs. Canadian System

Public Support by Income

Chairman ROCKEFELLER. Thank you, Bob.

Carroll?

STATEMENT OF CARROLL L. ESTES, PH.D., DIRECTOR, INSTITUTE FOR HEALTH AND AGING; CHAIRPERSON AND PROFESSOR, DEPARTMENT OF SOCIAL AND BEHAVIORAL SCIENCES, UNIVERSITY OF CALIFORNIA, SAN FRANCISCO, CA

Dr. ESTES. Thank you, Mr. Chairman. It is a great honor to be here and to speak to you about this very important problem of long-term care.

We have a dramatic set of projections for the catapulting of the size of the aging population. Some estimates would say that the number of elders will increase to 87 million persons by the year 2040, which would be 25 percent of the population. Within this process, those 85 and older are the fastest growing segment and indeed are expected to triple in their numbers to reach 18 to 24 million or 6.9 percent of the U.S. population by 2040.

Those who are 85 and older have basic chronic illness problems at a much higher rate than do those who are the young old. Indeed, approximately 40 percent of those 85 and older have difficulties with very basic activities of daily living, such as eating, toileting, dressing, or moving from the bed to chair or walking.

But more importantly, we are now coming to realize that long-term care is not just an aging issue, as you have heard eloquently demonstrated this morning. The composition of the long-term care population is now estimated to be 51 percent below age 65 and 49 percent above age 65. And indeed, studies indicate that there are few basic differences in terms of the needs of these two age populations for long-term care.

There is also a growing consensus among the Nation's leading epidemiologists that we face a paradox—one in which we have longer life but worsening health. There is increasing population frailty and some have even projected that for every 1 year of added good life, another 3.5 years of compromised life have been added.

We need to revise our thinking to fit the facts in order to recognize that long-term care is not just an aging problem, but that there is an intergenerational stake. There is a significant population that is impaired and needs long-term care which is not elderly, and there is a significant elderly population that also needs such care. And in addition, the caregivers of such people are both young and old. The Nation's backbone of long-term care is the personal private caregiver, family members, and mostly women. And two-thirds of these caregivers are below age 65. So younger caregivers are very much affected by the long-term care problem.

The needs in terms of long-term care for patients is, by definition, something that is not covered by most public policy—social services. Those inhome- and community-based services help with personal care, rehabilitation, home health aides, respite care, and adult day care among other things. Indeed, social services are health services. This long-term care population is extremely ill, and is, as I said, unable to do the many basic activities of daily living.

Most of this population lives in the community and it far behooves us to maintain this population in the community, lest we have to increase the cost of nursing home care dramatically. Public policy, regrettably, provides little protection for these chronically ill persons. There is literally no insurance, public or private, to protect against this liability and help individuals remain independent in the community.

If individuals need and use community-based long-term care, most of the cost will have to be paid by the family. And research indicates this can account for up to 91 percent of the expenses of community-based long-term care, because it is not skilled care and thus covered by Medicare or other payment sources. These services are much more in the area of attendant care, personal care, and help with these basic activities of daily living.

Government only covers 6 percent of these community-based services, because most programs cover only the skilled, acute care type inhome care. And Medicaid is extremely limited in its coverage, covers primarily nursing home care, and of course, has been accused of promoting dependency and impoverishment both in order for providers to receive the benefit. And so the total emphasis of Government programs tends to be toward nursing home care through the Medicaid Program.

In addition, private insurance cannot do the job, or at least has not done it to date, and estimates are that it is going to be very inadequate in dealing with long-term care. First of all, it is extremely expensive. Basic coverage is high cost, and age-related premiums tend to go up with age. Most cannot afford it. Estimates are that approximately 11 percent of the population over 65 have the $50,000 a year income necessary. This is 11 percent of couples, mind you, which have the $50,000 income it takes to buy a $2,000 a year long-term care policy.

But more importantly, there are preexisting conditions that limit eligibility for policies. There are extremely high turndown rates, estimated at 30 percent by private insurers, of people seeking long-term care coverage. The renewals on these policies is uncertain in many cases, at the company's option, and often conditional. And in some cases, insurers have dropped large classes of possible beneficiaries by rejecting an entire State or an entire class of beneficiaries.

In addition, there is limited coverage. Private insurance policies tend to be based on a mirror image of some of our Government policies so that there is very stringent use of nursing home benefits and much more support for the highly skilled benefits than for the inhome benefits.

So to close with what we need to do, long-term care is definitely a problem for all generations. There is no question the numbers of dependent elderly and nonelderly will continue to rise, and that informal caregivers will continue to bear most of the cost of long-term care. They're providing over 80 percent of the days of care for the chronically ill. In addition to that, as I mentioned, they're paying for over 90 percent of the caregiving costs for the chronically ill in the community.

With the increasing population frailty and the increasing need for women to be in the labor force, this is a very fragile basis for the Nation's long-term care policy. And indeed, it is at risk of collapse because of these caregivers, over 50 percent are working, and a large proportion of them already make work sacrifices themselves, limiting their own future coverage and social security and benefits, and are contributing substantially in a number of cases from their own financial income to try to support their elderly relatives.

So we have a need for formal care services, and we need public policy that will address the need for inhome and community services, those nonmedical social services, including geriatric assessment and personal care, attendant care, respite care, and adult day care that can keep people independent. The public, as the poll data has shown, as Dr. Blendon has reported, is more than ready for action, and the time is now.

We need a public provision and we need a social insurance base, and if we had to begin with one thing it would be to develop the support for the home- and community-based services. We need to protect this frail base of informal care that is given by families, and we need to have a broad insurance base that would make all in need eligible regardless of age and regardless of disease type or impairment type.

Thank you.

[The prepared statement of Mr. Estes follows:]

U.S. Bi-Partisan Commission
on
Comprehensive Health Care

Testimony by Carroll L. Estes, Ph.D.
September 1989

Carroll L. Estes, Ph.D.
Director, Institute for Health and Aging
Chairperson and Professor, Department of Social and Behavioral Sciences
University of California, San Francisco
94143

The author gratefully acknowledges the assistance of Elizabeth A. Binney, Susan Humphers, and Kristin Jacobson in the preparation of this testimony.

Testimony to the U.S. Bi-Partisan Commission on Comprehensive Health Care

By

Carroll L. Estes

September, 1989

Mr. Chairman and members of the Commission, it is my great privilege to present testimony on the nation's need for long term care. I am Professor and Chairperson of the Department of Social & Behavioral Sciences and Director of the Institute for Health & Aging at the University of California, San Francisco. For the past 25 years, I have been conducting research in the field of aging and health and have just completed a three-year study on the effects of Medicare prospective payment for hospitals on the ability of community-based long term care agencies to provide services to the elderly (Estes, Wood and Associates, 1988).

In my opinion, the U.S. is on a collision course in which the demographics of a rapidly aging society and increasing "population frailty" are colliding with an increasingly expensive medical care system, continuously rising costs of medical care, and the erosion of health care coverage for an increasing proportion of the population. The impoverishment and abandonment of the millions of Americans who need long term care are very real threats as a result. These trends are occurring in the face of our nation's failure to squarely address the need for a comprehensive policy on long term care and strong public opinion favoring action.

BACKGROUND: THE PROBLEM

The Need for Long Term Care Services Across the Life Span

I. Demographic Trends

The declining mortality rates and increasing life expectancy of the elderly population during this century are unprecedented in all of previous history. Currently, there are more than 29.8 million people over the age of 65, representing more than 12 percent of the population. Those aged 85 and older comprise the fastest growing age group in the U.S. Demographers' projections for the continuation and acceleration of these trends, particularly among the oldest-old, are alarming.

It is quite possible that in the next half-century, the number of Americans over age 65 could catapult to 87 million to become one-quarter of the population, according to NIA researchers (Guralnik, Yanagishita, and Schneider 1989). This projection is 20 million higher (and three times) that of the Census Bureau, based on an assumed decline in the mortality rate (the number of deaths per one thousand in a given population) of two percent a year. Based on the tripling of the over-85 population during the past 25 years, Guralnik et al. project that the population age 85+ will again triple in size during the next 40 years. According to Guralnik et al., by 2040, the number of individuals over age 85 could reach 23.5 million, comprising 27 percent of the over-65 population, although the Census Bureau conservatively estimates the over-85 population will number 12.8 million and comprise 19.2 percent of the over-65 population (See Figure 1).

These gains in life expectancy and declines in mortality rates have shocking significance for the long term care needs of the American population, as they have been offset by a rise in costly and disabling chronic diseases. The prevalence of non-life threatening but frequently disabling conditions increases with age (Kovar, 1977; Colvez and Blanchet, 1981; Verbrugge, 1984; Manton, 1987; Rice, 1986; Rice and LaPlante, 1987), and the "prevalence of functional dependency is greatest among the elderly" (EBRI, 1989; p. 4). Combined with the growth of the older population, the number of persons needing long term care is expected to triple between now and 2040. Health trends since the late 1950s suggest "a paradox between longer life and worsening health" (Rice 1986, p. 164; see also Verbrugge 1984). For example, Brody, Brock, and Williams (1987) have estimated that for each good, active functional year gained, about 3.5 compromised years are added to the life span.

In short, the data concerning mortality, morbidity, and disability trends present a disturbing picture of the health of the U.S. population. It is a picture of increased overall life expectancy of the elderly, but one that is characterized by only a modest addition to the years of active life expectancy (i.e., healthy, functioning years) and, on average, a substantial increase in the number of years lived with disabilities.

Other significant changes are occurring within the population that will influence the size and composition of the population needing long term care. The prevalence of functional dependence is approximately three percent in children under age 15. However, given the large absolute size of this population, it contributes a large numerical group (almost two million children) who need long term care services. Presently, children with severe chronic problems have interim needs for home care services that are not available (e.g., help in bathing) and that are not very well addressed by current public policy. An added problem is that the lack of health insurance has been found to be associated with adverse hospital outcomes for newborns, particularly for minority groups. This phenomenon potentially adds to the long term care burden, as the numbers of persons without health insurance continues to increase (Braveman et al., 1989). In addition, if the estimates of HIV exposure of 1 to 1.5 million persons (U.S. CDC, 1988) and the rate of progression to AIDS (of 36 to almost 50 percent within 8 to 10 years; Hessol, O'Malley, Lifson, et al., 1988; Cooper & Jeffers, 1988) are accurate, the nonelderly population with assistance needs in basic life activities will grow even more. The Centers for Disease Control (CDC) project that in 1992, about 172,000 persons will be living with AIDS (U.S. CDC, 1988), most of whom are expected to need assistance in basic life activities. The AIDS epidemic, which has affected primarily young adults, is contributing to a shift in the age distribution of the population needing assistance in basic life activities towards the nonelderly (LaPlante, 1989, p. 10), potentially magnifying the effects of population aging. If rates of assistance needs for those under age 65 are not reduced in successive age cohorts over the next several decades, the younger population with assistance needs will significantly enlarge the size of the disabled population in need of long term care as they themselves become increasingly older.

II. LONG TERM CARE AND FUNCTIONAL DEPENDENCE DEFINED

Long term care "encompasses the organization, delivery, and financing of many forms of assistance to people who are severely limited in their ability to function independently on a daily basis over a relatively long period of time" (EBRI, 1989; p. 2). Long term services are those health, social services, housing, transportation, income security, and other supportive services needed by those with chronic illnesses or disabilities. Services may be continuous or intermittent, institutional or noninstitutional, but delivered for a sustained period to individuals who have a demonstrated need, usually measured by some index of functional dependency (Kane and Kane, 1982). Chronic illnesses and conditions requiring long-term care are of an extended duration and lack medical specificity, such that chronic illness management becomes the primary problem. Community-based long term care services include home health care; homemaker, chore and personal services; occupational, physical and speech therapy; adult day care; respite care; friendly visiting; and nutritional and health education.

Important indicators of disability and the need for long term care are measures of functioning in physical activities and more complex activities which are essential to independent living. The most commonly accepted measure of need is functional dependence, based on one's ability to perform (1) essential activities of daily living (ADLs) including eating, bathing, dressing, toileting, getting out of bed, and moving around the home; and (2) more complex activities necessary to remain independent, or instrumental activities of daily living (IADLs), including shopping, cooking, laundry, managing household finances, and housekeeping. Although relatively few 65 year-olds report difficulty in perfoming basic activities, chronic illness is much more pervasive for those 85 and older, underscoring the import of making non-medical personal care services more available (See Figure 2).

Public and private financing mechanisms create an arbitrary distinction between long term care and other health services. Services which are covered (i.e., paid for) by Medicare or private insurance tend to be short term services, while long term services are excluded from coverage (Estes et al., 1983; Harrington, et al., 1985). Nevertheless, long term care services are the same services regardless of whether they are needed for a short or protracted period (IHA, 1989, p. 4).

III. THE NEED FOR LONG TERM CARE

One difficulty in fully and accurately projecting the need for long term care is that data collection has largely proceeded on the assumption that only the elderly are likely to need it. As Mitchell LaPlante has observed,

> "assessment of function in basic life activities is essential for estimating the demand for long-term care health and social services at all ages. Yet, assessment for long term care typically focuses on the elderly, presumably because the risk of loss of function in basic life activities is much higher for the elderly (which, of course, has been widely documented). This tendency is reflected in the shortage of nationally representative data on functioning in basic life activities in the nonelderly population. It should be recognized, [that] . . . [t]he population with assistance needs in basic life activities is more evenly distributed across the life span than is generally acknowledged" (LaPlante, 1989, p.1).

Researchers studying child health and the disabled adult populations have estimated that slightly more than half (51.2%) of the disabled are under age 65 (12.4% are under age 15) (EBRI, 1989). The remainder (48.8%) of the disabled population, defined as "noninstitutionalized persons reporting a limitation requiring assistance," is over age 65[1] (See Figure 3 and Table 1). Dr. Mitchell LaPlante, Director of the National Disability Statistics Program at the Institute for Health and Aging, has also concluded that a substantial proportion of the long term care population is under age 65. He estimates that the age distribution of this population, including those who reside in institutions, is 40 percent nonelderly and 60 percent elderly. Those under age 65 and in need of long term care include the functionally impaired and the developmentally, physically and mentally disabled (Rutgers and WID, 1988).

There are a variety of physical and mental conditions which necessitate long term care services. Disabilities from mental and cognitive impairments occur from a wide range of organic and neurological disorders such as Alzheimer's disease, AIDS dementia, and traumatic brain injury. Developmental disabilities are defined as those physical and/or mental impairments which manifest themselves before age 22, are likely to continue indefinitely, and result in three or more functional limitations: in self care, language, learning, mobility, self-direction, capacity for independent living, and economic insufficiency (U.S. Public Law 95-602). Mental impairments are usually categorized separately for purposes of public program eligibility, but these too are long term care programs.

Given that the proportion of persons who need long term care above and below the age of 65 are roughly equal, researchers argue that "the same human needs prevail regardless of age ... and [that we] should be wary about drawing ... artificial age distinctions" (Rutgers and WID, 1988, p 3; see also Zola, 1988). For example, the nonelderly have assistance needs that are higher than or at least equal to those of the elderly in both restriction of activity and health services utilization. Use of physician services is 50 percent higher among the nonelderly disabled than among the elderly. On the other hand, the elderly are more likely than the nonelderly to need someone at home to help in basic physical activities. Data from the National Health Interview Survey show that nearly 60% of the total non-institutionalized population age 65 and older reported some limitation in activity. It must be noted, however, that these data underestimate the prevalence of such conditions among the elderly population, since many of the sickest individuals, those who reside in nursing homes, were not surveyed. Nevertheless, the overall pattern of need for personal assistance services is remarkably similar between those age 18 to 64 and those age 65 and older who are living in the community (LaPlante, 1989). In rank order, these personal assistance needs are for: (1) housework (needed by 74% of those 18-64 and 80% of those 65 and older); (2) meal preparation (needed by 51% of the 18-64 and 60% of the 65 and older); (3) assistance in getting around (needed by 36% of 18 to 64 year olds and 58% of those 65+); and (4) personal care (needed by 32% of those 18-64 and 33% of those 65+)(Rutgers and WID, 1988, p. 7).

However, because of their high risk of chronic illness resulting in disability and functional impairment, older persons are the primary recipients of long-term care (Special Committee on Aging, U.S. Senate, 1989; p. 234). The U.S. GAO (1988) reports that in 1985, "of the 28.6 million elderly, an estimated 6.2 to 6.5 million depended on others for help with ADLs or IADLs or both" (p. 3). This represents almost one-quarter (22.7%) of the older population. About 2.6 million elderly were severely disabled, needing assistance with three or more ADLs.

Significantly, most of the elderly who are disabled do not reside in nursing homes. In 1985, less than one-quarter (21%) of the disabled elderly resided in nursing homes (Special Committee on Aging, U.S. Senate, 1989, p. 235), while almost 80 percent of the elderly with severe disabilities resided in the community. Of these, "about 850,000 elderly individuals were residing in the community with severe limitations (five or six ADLs)" (Special Committee on Aging, U.S. Senate, 1989, p. 237). This was possible because of the substantial amount of unpaid, informal care rendered primarily by women. Most important and often overlooked is the fact that "the great majority of long-term care services are provided by family members." (Special Committee on Aging, U.S. Senate, 1989, p 234). According to the 1982 National Long- Term Care Survey, nearly 90% of noninstitutionalized disabled elderly received assistance from relatives and friends, although in some cases it was supplemented by paid care (Special Committee on Aging, U.S. Senate, 1989; p. 234). Those living alone without formal caregivers are ten times more likely to be institutionalized than those who are married (Butler and Newacheck, 1981). Because those at greatest risk of entering a nursing home are those with difficulty with multiple ADLs, living alone, and 75 years or older (U.S. DHHS, 1986; p. 27), women are particularly vulnerable to institutionalization, given their greater longevity and propensity to live alone in comparison to older men.

THE LONG TERM CARE DELIVERY SYSTEM

IV. CHARACTERISTICS OF THE CURRENT SYSTEM

The financing and delivery of long-term care services in the U.S. is fragmented, piecemeal, and grossly inadequate to meet the needs of not only the current dependent population, but also the thousands of elderly who will survive to old age in the coming decades. This piecemeal approach has been criticized for its complicated and stringent eligibility requirements, multiple but incomplete sources of coverage, and inadequate information.

A major concern is the dominance of Medicaid, which historically has encouraged the delivery of care in nursing homes, requiring patients to become paupers in order to receive public assistance while often precluding their return to independent living (EBRI, 1989; p. 1). As a result, Medicaid promotes both the dependency and impoverishment of the elderly.

Yet, the availability of private insurance coverage for long term care - either for nursing homes or for their alternative, community-based care - is extremely limited to a small proportion of the elderly who can afford it (now estimated at less than one-half million persons). For those few who can afford private coverage, the exclusions and preconditions make it difficult for many to collect the long term care benefits under private insurance (Firman and Weissert, 1988). Those who are at greatest risk of needing long-term care (generally the oldest, the poorest, minorities and single females) can least afford this private coverage (Rivlin and Weiner, 1988).

Currently, a large proportion of the elderly who enter nursing homes and must privately pay for services subsequently spend down their resources so rapidly that they become eligible for Medicaid coverage within approximately 13 weeks of admission to a nursing home. Seventy percent of those living alone will "spend down" to the poverty level within this short three-month period, and nearly one-half of married couples will be impoverished after only six months of nursing home care for a spouse (House Select Committee on Aging, 1985) (See Figure 4).

There are other problems. In addition to the terrible cost burden of nursing home care, there is a shortage of nursing home beds for those who are (or become) Medicaid-eligible, primarily because Medicaid's low reimbursement rates make these patients undesirable. This is a particular problem in those states where Medicaid reimbursement rates are lower than fees charged to private pay patients (Scanlon, 1980; Harrington, 1985). As a result, issues of available supply, both of nursing home beds and community services for those who need long term care, will be paramount in the future health policy debate. Two facts underscore the point: (1) federal budget cuts in 1981 represented a true watershed, halting Medicaid expenditure growth rates, increasing variation between, and inequities among state Medicaid programs, and promoting a decline in access of the poor to medical services (Holohan and Cohen, 1986). (2) State efforts to control Medicaid costs have effectively put a lid on the supply of nursing home beds, and the number of beds per older person declined substantially between 1977 and 1985. For example, the number of beds per 1000 persons 85 and older declined fully 14% during this period (EBRI, 1989; p. 16). Further, by the year 2030, all of the existing 1.7 million nursing home beds could be filled with individuals aged 85 and older, assuming there are no changes in utilization patterns (EBRI, 1989).

There are at least 80 federal programs which assist people with long-term care needs, either directly through the provision of goods and services, or indirectly through cash assistance. However, the bulk of the publicly financed resources for services for the noninstitutionalized population (e.g., through Medicaid and Medicare) are designated only for services that are skilled in nature and for patients who are confined at home and who do not require full time or long term skilled care - and then only for health conditions considered unstable and related to recovery (i.e., non-chronic conditions). These policies have discouraged the development of an adequate supply of the full range of long-term care services needed to help people live independently at home (EBRI, 1989).

The Medicare Catastrophic Coverage Act of 1988 (P.L. 100-360) reflects a continuation of the preference of policy-makers to finance acute rather than long term care. The catastrophic care legislation lifted the 90-day limitation on long stay hospitalization. Several provisions are relevant to long term care: the extension of nursing home coverage by 50 days; the initial provision of a limited respite benefit; the removal of limitations in hospice days covered in terminal cases; and spousal protection against impoverishment. Despite the added benefits provided by the Act, not all catastrophic expenses are covered. "Most notably, it does not cover large and expensive stays in nursing homes" (Commerce Clearing House, 1988, p. 4). Interestingly, even with the new act, insurers of medigap policies "do not expect the catastrophic legislation to have a major impact on its approximately $13 billion in medigap policies" (Cooney, 1988; p. 8).

While the catastrophic act expands coverage in certain important areas (e.g., drugs and spousal impoverishment), some have estimated that it may benefit as little as one percent of the elderly population through coverage of services that are not highly utilized (Senior Action Leader, 1988). In contrast to a full social insurance model of financing that would spread the costs of the program across the entire population, the costs of the new legislation are to be borne solely by the elderly. Catastrophic coverage is funded primarily through increased monthly Part B premiums and increased tax liability for beneficiaries with higher incomes (Commerce Clearing House, 1988, p. 27). "Once a Medicare beneficiary has incurred out-of-pocket expenses exceeding the . . . Part B catastrophic limit (estimated to be $1370 in 1990), Medicare will pay 100 percent of all further reasonable costs or changes in that year" (Pierson, Ball and Dowd, 1988, p. 5). An important feature of the legislation is that for individuals below the federal poverty level of $5770 in 1988, state Medicaid programs are required to pay for Medicare deductibles and copayments.

When a chronic illness strikes, most older Americans will find that the long-term care services they need are not covered by Medicare, the new catastrophic benefit, other public programs, or private medigap insurance. Many elderly persons and their families pay the full costs out-of-pocket, making long-term care the "single greatest threat to the financial security of older Americans and many of their families" (Special Committee on Aging, U.S. Senate, 1989; p. 233).

The Need for Non-Medical Long Term Care Services

In the 1980s there has been a definite policy shift toward medical spending and away from other types of social service spending. The unabated rise in medical costs and reductions in spending for social services, from 1.5 percent of the GNP in 1976 to an estimated .84 percent of the GNP in 1992, has widened the gap and imbalance between expenditures on social and medical services. The problems inherent in the dearth of social services have been exacerbated by Medicare cost containment policies (e.g., prospective payment or DRGs). As hospitals have responded to incentives to discharge the elderly sicker and quicker, increased pressures have been placed on the already strained community-based social service system. A recent Institute for Health & Aging study on the effects of the earlier hospital discharge of the elderly with DRGs has documented: (1) dramatic increases in service demand from clientele who are physically sicker and older than previously and who have heavier care needs requiring more intensive, high tech, and skilled services than before, and (2) increasing difficulty by hospital discharge planners and other community providers in referring clients to needed services, and particularly for in-home care including homemaker/chore, home delivered meals and other forms of social services. In addition, many community-based service agencies report implementing access barriers for services not covered by public or private insurance including higher fees and copayments, tightened eligibility, and refusing services outright to clients who cannot pay (Estes, Wood and Associates, 1988).

The gap between public financing and the provision of medical versus the non-medical social services is most consequential for those needing long term care. "Even if expanded medical care stabilizes a chronic condition through good management, the everyday problems of living with that condition still remain." (Butler and Newacheck, 1981).

For the disabled elderly and nonelderly, it is the distinctly "social" services of personal care, nutrition, homemaker/chore and social support services that are most clearly linked to health. One recent study of chronically ill children discovered that, while special medical equipment play a significant role in assisting functionally impaired children and youth, the most common form of assistance utilized was help from another person. Overall, it was found that 86 percent of children with functional limitations relied on help from others in conducting at least one activity of daily living (Newacheck, Fox and McManus, 1988). This emphasizes the need for more home care services for chronically ill children similar to the service needs for adult and elderly disabled. Attendant services are one of the most important home care services for disabled people, with all levels of disability and at all ages. Since many disabled have the capacity to manage their own lives with some assistance, it is important not to think of the disabled as being sick, but as being disabled, and therefore capable of maintaining some control of their own lives. Attendant care and other home care services assist in maintaining the independence of the disabled, improving their overall quality of life and health.

There is an inherent danger in describing long term care services as something different from mainstream health services. Long term care services are integral to basic health care and are a part of a continuum of health and social services that are needed by those who are sick and disabled. The provision of personal care and social services, particularly those that would allow disabled persons to continue to live in their own homes and communities, is currently the weakest aspect of long term care service provision and is perhaps the most important.

Other findings emphasize the need for the public financing of (traditionally) non-medical, social, and mental health services for individuals suffering from chronic illnesses. For example, recent findings by Dr. Stewart of the Institute for Health and Aging and her colleagues at RAND (1989) and Wells, et al. (1989) indicate that individuals with non-medical conditions show significantly compromised physical, role, social and mental health functioning when compared with individuals displaying no such conditions. Stewart et al. found that "no matter which chronic condition a person has, it tends to be associated with adverse effects on most aspects of functioning and well-being" (p. 911), thus having profound individual and social costs in terms of the burden of unpaid care on family members and work loss. Wells et al. found that "[p]atients with either current depressive disorder or depressive symptoms in the absence of disaster tended to have worse physical, social, and role functioning, worse perceived current health, and greater bodily pain than did patients with no chronic conditions" (p. 914). Depression was found to have substantial clinical significance "comparable with or worse than that uniquely associated with eight major chronic medical conditions"; and depressive symptoms and medical conditions were found to have additive adverse effects. However, many clinicians consider depression to be distinct from and less medically significant than major chronic conditions. U.S. health policy reflects this bias and pays insufficient attention to the limitations caused by chronic conditions and depression. These findings are particularly crucial in light of new evidence of increasing prevalence of depression in the population at large (Klerman and Weissman, 1989). Mitchell and Anderson found that "mental, not physical, health problems are the most important reasons for the early withdrawal of older workers from the labor market" (270).

These findings underscore the need for policy changes that would provide treatment for such conditions, thereby improving patient outcomes, as well as the associated social costs, such as the negative changes in work behavior that are associated with poor mental health (Mitchell and Anderson, 1989). Thus, the provision of long term care which is oriented toward less medical and more social services can contribute to the well-being of individuals and have social benefits, as well.

An extremely relevant and exciting finding in support of non-medical services is Ken Manton's data indicating that between one-quarter to one-third of the chronically disabled are likely to manifest improved functional status over time (Manton, 1988; p. 223). Given the bias against rehabilitation and social supportive services contained in current health policy, it is reasonable to expect that, with concerted policy efforts directed toward interventions to improve functional status even for the permanently chronically ill, the proportion demonstrating functional improvements over time could well be significantly increased.

In sum, nonmedical services are essential and integral to basic health services for the old, and for adults and young persons who are disabled. There is an undeniable need to develop personal and social support systems and public policy to assure the financing and provision of social services and personal care (i.e. day care, homemaker, chore services, respite care, nutrition services, counseling) services to the elderly and nonelderly.

Federal policy and programs should be flexible enough to adjust to the needs of different age groups for both medical and non-medical services. Both population characteristics and the types of assistance needs call for ending the inequality between and separation of acute and long term care and both argue against a division between the elderly and nonelderly in future health policy.

V. THE FINANCING AND PROVISION OF LONG-TERM CARE

When examined as a proportion of the GNP, the amount of spending devoted to long term care is truly miniscule, at less than five-tenths of one percent (0.45%) (Weiner, 1987). Expenditures for long-term care (Senate Special Committee on Aging, 1989, pp. 238-239) for all age groups were $44.9 billion in FY 1985. Most of this amount, $35.8 billion (80%), was for nursing home care, while $9.1 billion (20%) was for home health services (defined as nursing care, home health aides, medical social services, and speech, physical and occupational therapy). Direct out-of-pocket payments paid for 45% of the cost of nursing home care and 50% of the cost of formally provided home health care (GAO, 1988, p. 32). Private long-term care insurance paid only eight-tenths of one percent of the costs of nursing home care and 4% of the costs of home health care. When the full array of formally paid long term care in the community is considered, only 25% is financed through government sources (Liu, Manton and Liu, 1985). However, when community-based long term care costs are analyzed by source of payment, the government share is much smaller (6%), while 91% is paid for by the elderly or relatives (See Figure 5).

Nationwide nursing home costs are expected to triple, from its present $33 billion in 1986-90 to $129 billion by 2000, but the share covered by private insurance is expected to remain quite small (5%), and individual out of pocket costs will rise to 53% as Medicaid's share drops to 35% (US Senate Special Committee on Aging, 1987, p 31). A persistent problem has been that the rapid rise in health care costs has consistently outstripped rises in the cost of living adjustments in Social Security. Similarly, long-term care costs are expected to rise more rapidly than the incomes of the old-old. As a consequence, those 85 and older who are most likely to need long-term care in the future will be worse off financially than the elderly today - even though they will have higher incomes (Special Committee on Aging, U.S. Senate, 1989; p. 239).

The vast majority of long term care services are performed informally (unpaid) by family, friends, neighbors, and volunteers. It is estimated that more than 27 million days of informal care are provided each week (1.4 billion each year) (Special Committee on Aging, U.S. Senate, 1989; p. 238). Over 70% of the non-institutionalized disabled elderly rely exclusively on unpaid sources of home and community health care. Most informal caregivers are women - usually wives, daughters, or daughters-in-law. Providing constant care for a disabled person incurs great physical and emotional stress, and may also have adverse financial impact. Caregiver stress and exhaustion are significant factors precipitating institutionalization (Special Committee on Aging, U.S. Senate, 1989; p. 238). While nearly one million received some paid care in 1985, only 240,000 used formal (paid) care exclusively. Of those receiving any formal community care, Medicare covered 8.4 percent and Medicaid paid for 6 percent, respectively, of the cost of this care. Private insurance covered less than any other source.

Basic Principles

The nation wants and needs a publicly financed long term care system. It should be built upon the following basic principles:

- Provide services along a full continuum of long term care services, both medically and socially oriented, with a goal of maximizing functional independence and preventing illness and disability;
- Integrate acute, ambulatory, and long term care services;
- Provide care and financial protection for all ages, disability groups and income groups, that is, universal coverage;
- Use mechanisms and incentives to control costs and reimbursement rates to ensure that care is affordable;
- Promote high quality services and appropriate utilization, in the least restrictive environment;
- Use a financing system that is progressive and that spreads the risk for financing across the entire population;
- Encourage delivery systems that are coordinated, accessible, innovative, consolidated, and efficient;
- Acknowledge, support and reward families and friends who provide informal care; and
- Provide advocacy services to ensure access to appropriate services.

POLICY RECOMMENDATIONS

> "We need to create a health care system that will deliver care based on need, rather than the ability to pay to the people of our country. That is the critical issue that faces our nation as the United States grows older."
> Representative Claude Pepper

I. FINANCING

1. Funding should be through a national universal social insurance system (ideally integrated with the current Social Security system and/or the financing of other health care programs) to insure stable and adequate funding over time. The eventual integration of current public systems of care should be the goal.

2. Public funding must be the cornerstone of the program and expansion of public financing is necessary, including a possible expansion of the Medicare program (but in such a way that it includes all age groups). Private financing would be incrementally reduced to a basic role of asset protection. The goal of eliminating the current pluralistic payer system (one of the major reasons for escalating costs) should be primary.

3. Cost controls, including managed care, transferring financial risk to providers, regulation of payments and financial disclosure of income, costs and earnings, need to be an integral part of the financing system.

4. Financing should be based on the principle of taxing the general population (and not solely the elderly or disabled). Some specific

possibilities for financing of the estimated $20 billion increase over Medicare, Medicaid and other public programs that a comprehensive social insurance long term care program would cost in 1990 are (Ball, 1989):

a) increasing the Social Security contribution rate by .75% equally matched for employers and employees

b) dedicating personal and corporate taxes, increasing current rates from 15 to 16 percent and 28 to 30 percent (this would raise $30 billion in 1990); a 5% surtax on the corporate income tax would add another $5.7 billion.

c) removing the cap on earnings subject to Social Security taxes and/or removing the cap on the employer's share of the tax. Doing both would raise approximately $49 billion in 1990; while raising only the employer's cap (for public support purposes) would, in the short run, produce half as much revenue but, in the long run, would raise about as much as if the cap were lifted for both (because unlike worker's contributions, employer's contributions are tied to benefits).

d) increasing taxes at death (a 10% surcharge on gifts and estates over $200,000 would raise $4 billion in 1990 and a tax on capital gains at death would raise about $5.5 billion).

e) increasing the taxation of Social Security benefits paid to higher income beneficiaries. Raising the percentage of taxable benefits for higher income beneficiaries from the current 50% to 85% would raise $3.1 billion in 1990 and lowering the income threshold from the current $25,000/$32,000 to $12,000/$18,000 would produce $9 billion in 1990.

5) Financing should involve mandatory participation in order to insure adequate financing and public support, universal coverage regardless of income or perceived health status, and problems such as adverse selection.

6) Financing should be adequate enough to greatly reduce and eventually eliminate premiums, co-payments and other regressive out-of-pocket costs. A notable exception might be the use of user income or other resources for board ("hotel") costs in nursing homes.

7) The system should adopt principles of prospective payment and the curtailment of fee-for-service health care, not only to control costs, but because they offer (with proper quality of care incentives and mechanisms) the better potential for improved health care delivery and health status.

II. BENEFITS/SERVICES

1) Services should include a uniform benefit package of social and medical services, institutional and community-based care.

2) The spectrum of institutional services should include: Independent Living Centers (ILCs), foster care, board and care, assisted living, residential care facilities, nursing homes, state hospitals, chronic care hospitals, and rehabilitation facilities.

3) The spectrum of community-based benefits should include: diagnostic services, care management, meals, information and referral, in-home support services (homemaker and attendant), protective services, respite, senior companions, transportation services, home health, and adult day care.

4) Case management services should be included as integral, including assessment, planning, service coordination and/or referral, monitoring, and reassessment of clients.

III. ELIGIBILITY

1) Eligibility should be based on the principle of universality, with the entire population covered regardless of age, disability or income, where services are made available to all who meet criteria defining long term care need.

2) Disability/need criteria should be sufficiently broad so that no one currently receiving services would be denied access to needed long term care and should consider both physical and cognitive impairments as well as the availability of informal care and social supports.

3) Utilization controls should be closely monitored in order to assure access and care for those in need of service. While necessary for the efficient running of the system, gatekeeping systems should be combined with services such as case management, I&R, care coordination and ombudsman services as appropriate. Cost sharing as a utilization control tends to be regressive and ultimately may cost the system and thus should be avoided.

IV. DELIVERY SYSTEM

1) The current fragmentation of the long term care delivery system is a primary concern and should be the object of scrutiny and innovative policy initiatives.

2) Initially, one approach that should be encouraged is the "brokered system" model which attempts to coordinate services among provider organizations in a community.

3) Ultimately, a consolidated delivery model, in which services are provided by a single organization, needs to be developed to cut costs, but to eliminate the false and unproductive dichotomy between acute and long term care services.

4) Quality control mechanisms are crucial to the long term care system and should be given close, prospective attention. Regulatory mechanisms must be given strong powers of investigation and enforcement,

and incentives for quality care should be developed including stronger educational requirements, internal quality assessment systems, and adequate advocacy mechanisms.

CONCLUDING OBSERVATIONS

Mr. Chairman and Commissioners, several conclusions are obvious:

(1) Despite varying estimates and population projections of the need for long term care, there is considerable agreement that the number of dependent elderly and nonelderly will continue to rise; indeed, the future is certain to be one characterized by increasing population frailty and a growing population in need of long term care.

(2) In spite of the fact that the predominant share (approximately 84% of the days of care, US Senate, 1988, p. 121) of long term care is provided by family and friends (mainly women) and the realistic assumption that informal caregivers will continue to perform the predominant share of long term care services the dependent populations, it is safe to assume that there will be a steady growth in the proportion of the population that will have to rely on formal services.

(3) Without significant policy changes, most of the population in need of long term care will have difficulty obtaining it. Public programs provide only limited long term care benefits and private insurance is limited and unaffordable by most of the population who will need it.

(4) Access to long term care is a crucial problem that, without remedy, can only be expected to grow. The current delivery system is being swamped by large numbers of extremely sick elderly being discharged from the hospital more quickly, and with reimbursement mechanisms that discriminate against social services and the treatment of chronic illness in both the home and community, regardless of age (young, middle aged or the old);

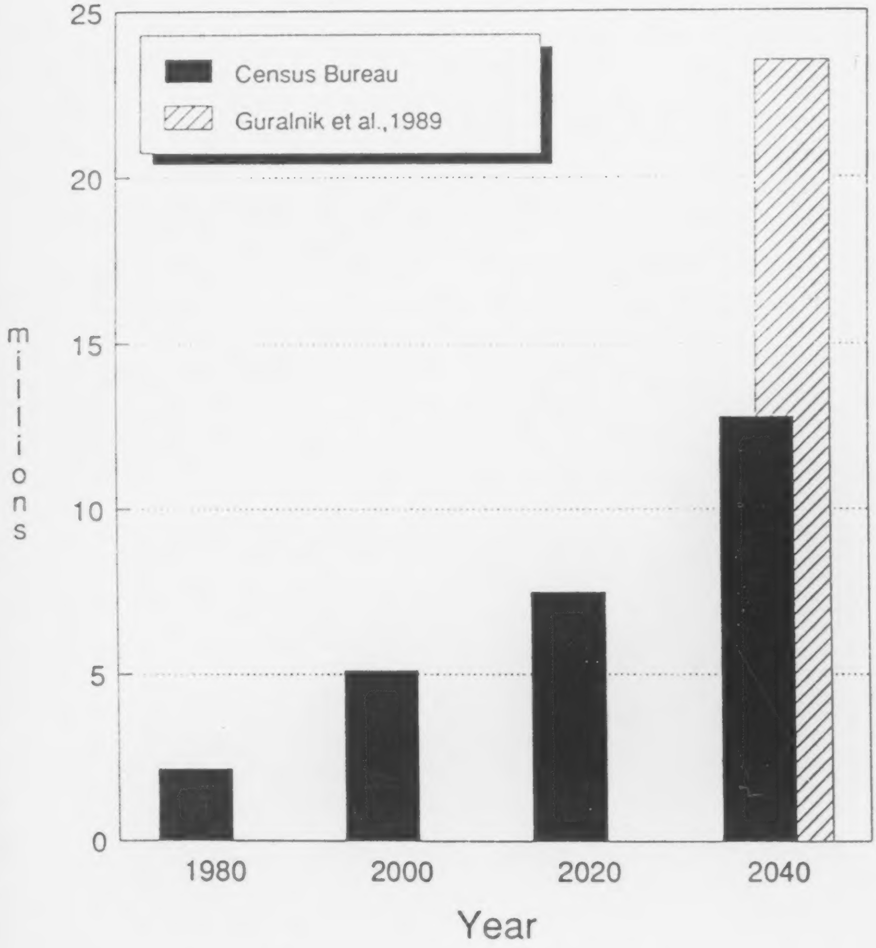
(5) The American public is ready for major policy action in the health care arena. More than half (51%) of Americans polled in 1984 indicated that "fundamental changes are needed to make the health care system work better" and in another poll, 31% noted that "the American health care system has so much wrong with it that we need to completely rebuild it" (Harris and Associates, 1983; Schneider, 1985; Taylor, 1986). Other national polls on long term care corroborate these views: At least four such surveys, including one from younger generation readers of Rolling Stone magazine agree "that the public not only wants government support for long term care, but is willing to pay for it through higher taxes" (Congressional Quarterly, 1988, p 938). Advocates for universal health care for Americans of all ages and advocates for the elderly will continue to press for federal solutions to the problems of the uninsured and of the rising costs, the inadequate and eroding benefits of the underinsured, and the need for long term care.

Notes

[1] 10.9% of those over age 65 are 65 to 69; 10.9% are 70-74, and 27.0% are 75 and older (Rutgers and WID, 1988, p 3).

FIGURE 1

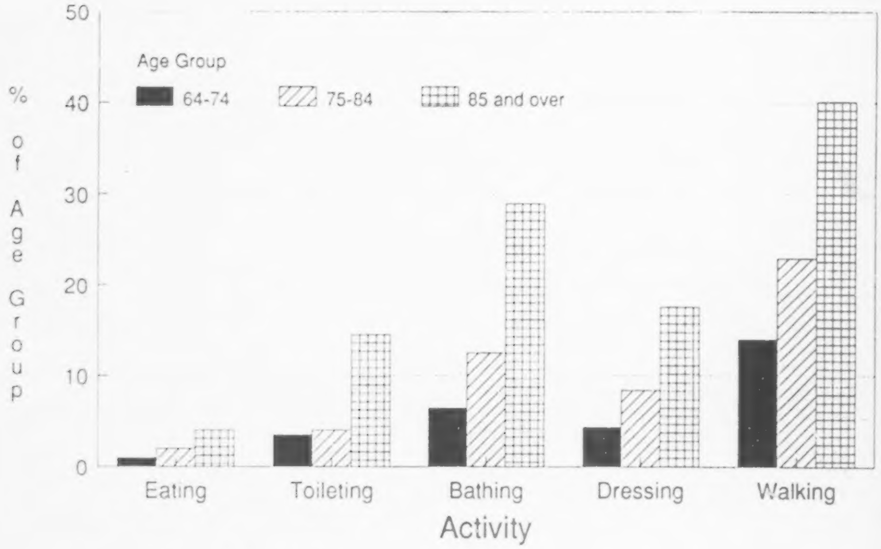
GROWTH OF THE OLDEST OLD POPULATION: 1980 - 2040



Source: Ball, 1989.

FIGURE 2

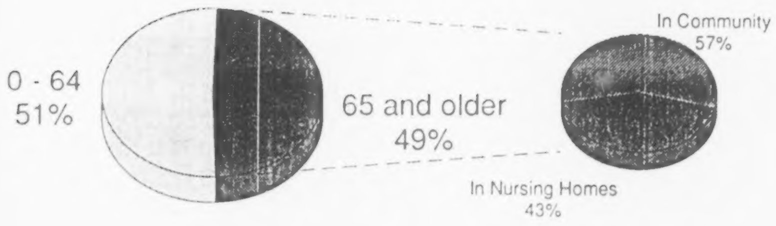
WHEN AN AGING POPULATION NEEDS A HELPING HAND



Source: NCHS data from Ball, 1989.

FIGURE 3

THE LONG TERM CARE POPULATION, BY AGE AND LIVING ARRANGEMENT



Source: Ball, 1989.

Table 1

Prevalence of Functional Dependence among
the Noninstitutionalized Population, 1984

Age Group	Population with Limitations[a] (in thousands)	Percentage among the Disabled	Percentage within Each Age Group
Total	15,452	100.00%	6.35%
Under 15[b]	1,916	12.40	3.07
15-24	346	2.24	0.88
25-34	596	3.86	1.47
35-44	890	5.76	2.92
45-54	1,431	9.26	6.43
55-64	2,734	17.69	12.39
65-69	1,682	10.89	18.84
70-74	1,691	10.94	22.92
75+	4,166	26.96	41.18

Source: EBRI tabulations from data in U.S. Department of Commerce, Bureau of the Census, Disability, Functional Limitation, and Health Insurance Coverage: 1984/85. Current Population Reports, series P-70, no. 8 (Washington, DC: U.S. Government Printing Office, 1986), tables C and H (EBRI, 1989).

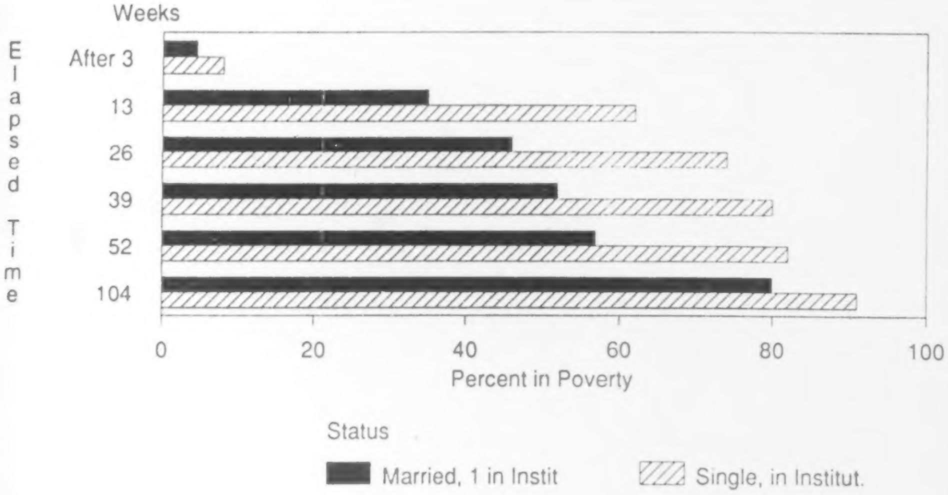
[a] Limitations for persons aged 15 or older are based on the need for assistance from another person in doing light housework, preparing meals, dressing, eating, personal hygiene, or being mobile.

[b] Limitations for children are based on whether or not the child had a long-lasting physical condition or mental or emotional condition that limited walking, running, playing, or learning to do regular schoolwork.

FIGURE 4

FINANCIAL RISK OF LONG TERM CARE

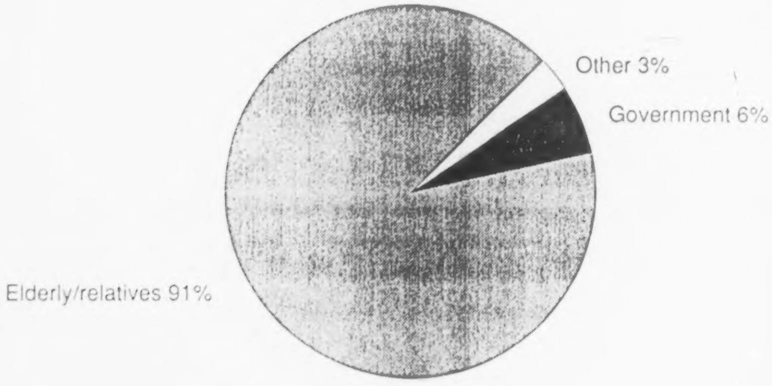
Weeks to Poverty: Percent of Elderly Impoverished Over Time



Source: U.S. House Select Committee on Aging, 1985

FIGURE 5

COMMUNITY-BASED LONG TERM CARE COSTS, BY SOURCE OF PAYMENT



Source: 1982 Long-Term Care Survey

REFERENCES

A.S.A.P. (1988, June). "Ready for President's Signature: Congress Clears Catastrophic Bill." Advocates Senior Alert Process. 4(2):1-3.

Ball, Robert M., with Thomas N. Bethell. (1989). Because We're All in this Together: The Case for a National Long Term Care Insurance Policy. Washington, DC: Family U.S.A. Foundation.

Braverman, Paula, Geraldine Oliva, Marie Grisham Miller, Randy Reifer, and Susan Egerter. (1989, August 24). "Adverse Outcomes and Lack of Health Insurance among Newborns in an Eight-County Area of California, 1982-1986." The New England Journal of Medicine. 321(8):508-512.

Brody, J.A., D.B. Brock and T.F. Williams. (1987). "Trends in the Health of the Elderly Population." In L. Breslow, J.E. Fielding, and L.B. Lave, eds., Annual Review of Public Health, Volume 8. Palo Alto, CA: Annual Reviews, Inc., pp. 211-34.

Butler L.H. & Newacheck P.W.(1981). "Health and Social Factors Relevant to Long-Term Care Policy." In J. Meltzer, Frank Farrow & Harold Richman, eds., Policy Options in Long-Term Care (pp. 38-77). Chicago & London: University of Chicago Press.

Colvez, A. and M. Blanchet. (1981). "Disability Trends in the United States Population 1966-76: Analysis of Reported Causes." American Journal of Public Health 71:464-71.

Commerce Clearing House. (1988). "New Medicare Benefits: Medicare Catastrophic Coverage Act of 1988." Chicago, IL: Commerce Clearing House.

Congressional Quarterly. (1988). "Law Makers Taking Hard Look at Problem of Long Term Care." Congressional Quarterly 46(15): 938-940.

Cooney, Bente. (1988, July/August). "The New Catastrophic Health Coverage: Winners and Losers." The OWL Observer. 7(4):1-8.

Cooper, G.S. and D.J. Jeffers. (1988). "The Clinical Prognosis of HIV-1 Infection: A Review of 32 Follow-Up Studies." Journal of General Internal Medicine 3(6): 525-532.

Employee Benefit Research Institute Issue Brief. (1989, January). "Issues Concerning the Financing and Delivery of Long-Term Care." No. 86.

Estes, C. L., J. B. Wood and Associates. (1988). "Organizational and Community Responses to Medicare Policy." Final Report, Vols. I, II, and III. San Francisco, CA: University of California, Institute for Health & Aging.

Firman, James and William Weissert. (1988). "Private Long Term Care Insurance: How Well is it Meeting Consumer Needs and Public Policy Concerns?" Washington, DC: United Seniors Health Cooperative (Sept).

Guralnik, Jack M., Machiko Yanagishita, and Edward L. Schneider. (1988) "Projecting the Older Population of the US: Lessons from the Past and Prospects for the Future." Milbank Memorial Quarterly, 66(2): 283-308.

Harrington, Charlene. (1985). "Crisis in Long Term Care: Part 1, The Problems." Nursing Economic$ (Jan/Feb) 3(1): 13-20.

Harris and Assoc. (1983; 1985) Equitable Health Care Survey. Washington, D.C.: Equicor.

Hessol, N.A., P.M. O'Malley, A.R. Lifson, et al. (1988). "Projections of the Cumulative Proportion of HIV Infected Men Who Will Develop AIDS." 28th Interscience Conference on Antimicrobial Agents and Chemotherapy, Los Angeles, CA, October 23-26.

Holohan, John and J.W. Cohen. (1986). Medicaid: The Trade-Off Between Cost Containment and Access. Washington, DC: Urban Institute Press.

Institute for Health & Aging. (1989). Long Term Care Public Policy Options for California: Background Paper. San Francisco, CA: University of California, Institute for Health & Aging.

Kane, Robert A., and Rosalie L. Kane. (1982). Values and Long Term Care. Lexington, MA: Lexington Books.

Kovar, Mary Grace. (1977). "Elderly People: The Population 65 Years and Over." Health, United States, 1976-77. DHEW Pub.No. (HRA)77-1232. Hyattsville, MD: National Center for Health Statistics.

Liu, Korbin and Kenneth Manton. (1987). Current Estimates and Projections. In Developments in Aging: 1987, Volume 3, U.S. Senate Special Committee on Aging, January 28, p 8.

Liu, Korbin and Kenneth Manton. (1983). "The Characteristics and Utilization Pattern of an Admission Cohort of Nursing Home Patients," The Gerontologist, February.

Liu, Korbin, Kenneth Manton, and Barbara Marzetta Liu. (1985). "Home Care Expenses for the Disabled Elderly." Health Care Financing Review 7(2) (Winter).

LaPlante, Mitchell P. (1989, January). "Disability in Basic Life Activities Across the Life Span." Disability Statistics Report 1: 1-42.

Manton, Kenneth. (1987) "The 1982 and 1984 National Long Term Care Surveys: Their Structure and Analytic Uses," Paper presented at Health and Human Services Conference on Long Term Care Data Bases, Washington, DC.

Manton, Kenneth. (1988) "Planning Long Term Care for Heterogeneous Older Populations," Annual Review of Gerontology and Geriatrics, Volume 8. New York: Springer Pub Co., pp217-255.

McKinlay, John, Sonja McKinlay, and R. Beaglehole. (1988). "Trends in Death and Disease and the Contribution of Medical Measures. In H.E. Freeman and S. Levine (eds.), Handbook of Medical Sociology. Englewood Cliffs NJ: Prentice Hall, pp 14-45.

Meltzer, J., Farrow, F., & Richman, H. (1981). Policy Options in Long-Term Care. Chicago & London: University of Chicago Press.

Meltzer J.W. (1988) "Financing Long Term Care: A Major Obstacle to Reform. In S. Sullivan & M.E. Lewin (Eds.). The Economics and Ethics of Long Term Care and Disability (pp. 56-72). Washington, DC: American Enterprise Institute for Public Policy Research.

Mitchell, Jean M. and Kathryn H. Anderson. (1989, Summer). "Mental Health and the Labor Force Participation of Older Workers." Inquiry. 26:262-271.

Newacheck, P.W., Fox, H.B and McManus M.A. (1988). "Home Care Needs of Chronically Ill Children." Caring, June 1988.

Pierson, Ball & Dowd. (1988, June 20). "Legislative Update: Medicare Catastrophic Coverage Act of 1988 and Related Legislation." Washington, DC.

Rice, Dorothy. (1986) "Living Longer in the U.S.: Social and Economic Implications." Journal of Medical Practice Management, 1(3): 162-169.

Rice, Dorothy and Mitch LaPlante. (1988). "Chronic Illness, Disability and Increased Longevity." In S. Sullivan and M. Ein Lewin (Eds.), The Economics and Ethics of Long Term Care and Disability. Washington DC: American Enterprise Institute for Public Policy, pp. 9-55.

Rice, Dorothy P. and J.J. Feldman. (1983). "Living Longer in the United States." Milbank Memorial Quarterly 61(3).

Rivlin, Alice and J.M. Weiner. (1988). Caring for the Disabled Elderly. Washington DC: The Brookings Institution.

Rutgers University and World Institute on Disability. (1988) Towards an Understand of the Demand for Personal Assistance. New Brunswick, NJ: Rutgers Bureau of Economic Research and Berkeley Ca: World Institute on Disability.

Scanlon, William. (1980). "A Theory of the Nursing Home Market." Inquiry 17(2): 25-41.

Schneider, Ed. (1985). "Public Ready for Real Change in Health Care." National Journal 3(3): 664-665.

Senior Action Leader. (1988, September). "Catastrophic Health Bill: Just the First Step." Boston, MA: Massachusetts Senior Action Council, pp. 1, 6-7.

Stewart, Anita L., Sheldon Greenfield, Ron D. Hays, Kenneth Wells, William H. Rogers, Sandra D. Berry, Elizabeth A. McGlynn, and John E. Ware. (1989, August 18). "Functional Status and Well-Being of Patients with Chronic Conditions." Journal of the American Medical Association 262(7): 907-913.

Stone, Robyn I., L. Cafferata, and J. Sangl. (1987). "Caregivers of the Frail Elderly: A National Profile." The Gerontologist, 27(5): 616-626.

Stone, Robyn I. and Christopher M. Murtaugh. (Unpublished paper, 1988). "The Elderly Population with Chronic Functional Limitations: Implications for Home Care Eligibility." National Center for Health Services Research and Health Care Technology Assessment.

Taylor, Humphrey. (1986). Testimony before the U.S. House Select Committee on Aging, Washington, D.C., April 8.

United States Bureau of Census. (1984). "Projections of the Population of the United States, by Age, Sex, and Race: 1983 - 2080." Current Population Reports, Series P-25, No. 952. Washington DC.

United States Center for Disease Control (CDC). (1988). "Quarterly Report to the Domestic Policy Council on the Prevalence and Rate of Spread of HIV and AIDS -- United States." Morbidity and Mortality Weekly Report 37(36): 551-559.

United States Department of Health and Human Services, Public Health Service, National Center for Health Statistics. (1986). "Health Statistics on Older Persons: United States, 1986." Series 3, No. 25. Hyattsville, MD: U.S. Department of Health and Human Services.

United States General Accounting Office. (1988, November). "Long-Term Care for the Elderly: Issues of Need, Access, and Cost." Washington, DC: U.S. General Accounting Office.

U.S. Senate Special Committee on Aging. (1987). Developments in Aging, Volume 3. Washington, DC: U.S. Government Printing Office.

U.S. Senate Special Committee on Aging. (1989). Developments in Aging: 1988, Volume 1. Washington, DC: U.S. Government Printing Office.

Verbrugge, Lois. (1984). "Longer Life But Worsening Health? Trends in Health and Mortality of Middle-Aged and Older Persons." Milbank Memorial Fund Quarterly 62: 475-519.

Verbrugge, Lois. (1989). "Recent, Present, and Future Health of American Adults." In, J.E. Breslow, J.E. Fielding, and L.B. Lave, eds., Annual Review of Public Health, Volume 10. Palo Alto, CA: Annual Reviews, Inc.

Villers Foundation. (1987). On the Other Side of Easy Street. Washington, DC: The Villers Foundation.

Wells, Kenneth B., Anita Stewart, Ron D. Hays, Audrey Burnam, William Rogers, Marcia Daniels, Sandra Berry, Sheldon Greenfield, and John Ware. (1989, August 18). "The Functioning and Well-Being of Depressed Patients." Journal of the American Medical Association 262(7): 914.

Wiener, Joshua. (1987). "We Can Run, But We Can't Hide: Financing Options for Long-Term Care." Testimony presented before the Budget Comittee, U.S. House of Representatives, Oct. 1.

Zola I.K. (1988). "Policies and Programs Concerning Aging and Disability: Toward a Unified Agenda." In S. Sullivan & M.E. Lewin (Eds.), The Economics and Ethics of Long Term Care and Disability. Washington, DC: American Enterprise Institute for Public Policy Research, pp. 190-230.

Chairman ROCKEFELLER. Thank you, Carroll, very much.

I'll call on Senator Durenberger for any questions that he might have.

Senator DURENBERGER. I better forego questions, Mr. Chairman.

Chairman ROCKEFELLER. All right.

Carroll, let me just ask a question. If decent home care were available, one argument that's thrown up from time to time is that families would then step out of the loop. I want to believe that is not true.

Dr. ESTES. Well, fortunately, we were in the position now to have a number of significant research projects funded by the National Institute on Aging——

Chairman ROCKEFELLER. And what do they tell us?

Dr. ESTES [continuing]. That answer that question. They indicate that, in fact, quite the contrary, that when formal support is available to assist families, that it is possible for the informal caregivers to continue providing care long after they would have otherwise had to give up from exhaustion, both physical, emotional, and financial. So indeed, there is a positive benefit from the formal service provision, as opposed to a negative benefit.

Chairman ROCKEFELLER. You are both pessimistic, it sounds to me, in terms of the private insurance industry and its ability to respond. In fact, we have more and more policies being offered and aiming at smaller and smaller niches. Is there realistically—well, let me ask you two questions.

Is there an instinct—when insurance companies get together to talk about things, do they talk about: "Hey, there's something really wrong here in our American health care system and we've got to face up to this. And if we don't, somebody's going to come in and give us a Canadian system or English system or something else and we aren't going to be around at all." And therefore, are they thinking about this and adjusting their policies not just for the sake of profit but for the sake of really their own long-term survival.

Because my own view is that there is a rage in this country which is building which really has been there for a long while, a little bit like our trade deficit. We've had a trade deficit with Japan since 1962, but we really didn't focus on it until 1984. You know, it takes a long time for the people to get mad, but when they do, watch out. And we may be at precisely that point now, catastrophic care having symbolized the frustration in so many ways.

In terms of the insurance industry, are they capable of, on the one hand, are they in the business of, on the other hand, of looking at their futures realistically and adjusting? I'd ask that to either of you or both of you.

Mr. BLENDON. I don't want to be accused of representing the insurance industry. So if you had Carl Schramm here, who represents HIAA [Health Insurance Association of America], I believe he would say that the industry has come forward with a bill which resembles, to my less intense look, something like a mandated bill. And I think they would try to say to you that many of the problems we discuss today, as with automobile insurance, can't be a substitute for one of two things: One, Government requiring everyone to carry automobile insurance; and two, Government providing public availability or support for people who can't afford to buy it.

So I think there's an awareness among a key group in the health insurance industry that this thing is unraveling. But it will not be settled in the private marketplace. That is, as long as a small business can say: "You've got to sell me a policy that does a blood test and asks every one of my employees if they have cancer or heart disease or tells them to walk up the steps and if they can't get up there we don't give them the policy." As long as that exists in the American marketplace, meeting together is not the answer.

We have to have either the Government providing the insurance, where the current rage is building, or basically a set of requirements like with automobile insurance which says: "Everybody that drives or works has a policy. These are the ground rules. Employers cannot ask about cancer, AIDS, or heart disease."

Dr. ESTES. And particularly concerning long-term care, because it is reasonable to expect that young people will not purchase long-term care policies, because they can anticipate 20 or 30 years before they might need it. It wouldn't make sense for them to purchase it on a voluntary basis.

It means that the policies are going to continue to be very high and out of reach for most elderly, because the base that will be supporting those policies are the policyholders most at risk, which means the costs are going to remain very high and unattainable by most elderly.

Chairman ROCKEFELLER. You both raise an interesting point there, because we're all suggesting the rage is there and Bob, you showed it through the numbers. I think that was 11 percent of Americans are satisfied with our health care system, and in Canada it was, what, 40 percent, and England 60 percent or something of that sort? So that really defines frustration, concern, and in some cases rage.

And then on the other hand, you have this fascinating dilemma that we've been through in the last several weeks and will be dealing with in the next several days called catastrophic health insurance. If there is anything that is clear on paper, it is that only 5.6 percent of people will be paying a supplemental premium of $800, and it is known to everybody that works in this building and everybody that works in this city inside this beltway and a lot of people on the outside and a lot of senior groups.

But they are dealing with a return of rage, which says: "I cannot pay. I will not pay." In fact, it is not coming from the flat premium people, it is coming from the 5.6 percent who are making $400,000 a year or whatever.

So on the one hand, people are angry. The polls prove that. On the other hand, people don't want to pay. Catastrophic proves that. We want to sort of fix the system up really quickly, because we have a feeling that the rage is well justified. And yet, we could make serious mistakes in a so-called rush to judgment.

What, Carroll, would you have us do about uninsured, since that's not your topic?

Dr. ESTES. I think the question of the uninsured is one of the most important issues that must be on the agenda of everybody who's concerned about the Nation's elders, as well as young people.

Because, the fact that we don't offer prenatal care and we have children born with all sorts of problems is creating a long-term care problem for an entire lifetime that is going to be very costly.

So I think we absolutely—the first priority, if I had to name one, would be prenatal care and care for the first few years of life as an absolute essential. But I do think it is quite consonant with the overall need for addressing what are long-term care needs when inhome- and community-based care is required.

So I think we need to move on the uninsured, and we need to move on long-term care. And if we had to start incrementally, there are basic steps that I would recommend first. But on the long-term care side, I would recommend first the inhome- and community-based services. And on the uninsured, I think we've got to deal with this 37 million with no insurance. And certainly, we should be starting, if we have to start in increments, with the prenatal care in the first years of life health care.

Chairman **Rockefeller**. Bob, one question, and I guess final question, since Dave is gone, to you.

Medicaid takes care of less than half, I think it's 42 percent, of the poor. And in theory, it's meant to do it all. Governors say: "Whoa, we've got enough on our backs already." So people start looking at other solutions. And then suddenly, you discover that firms that have 25 or fewer people—in fact, construction, retail, entertainment, things of this sort, small employers—that they can't afford it.

The minimum wage argument says if you increase the quality of access or life for some in certain ways, then there's going to be another penalty because some people will go out of work. And in fact, in minimum wage increase, which I in fact support, the evidence is clear that there will be job loss.

What is the moral or the ethical dimension that we should face as a Commission in dealing with the small businessperson who is struggling and cannot make enough money in their judgment to provide health insurance? What ethically, morally, must I worry about that?

Mr. **Blendon**. Are you asking me to look at it from the point of view of the small businessperson?

Chairman **Rockefeller**. Yes. Well, as a policymaker. Including that point of view, how would you react to what I've asked?

Mr. **Blendon**. The first thing is, I had a chance to ask the Japanese Minister of Health exactly the same question. I asked him first of all about all the small businesses they have in Japan. They do not have a central government system. I know we all want to believe it looks like England or Canada out there. It doesn't. They basically require all the employers to cover insurance through one fund or other. And very small businesses get a tax credit and a subsidy.

And I asked him were the small businesses in favor of this. Absolutely not. So let's get that off the table. There is nowhere in any part of the world that the people who run small laundries volunteer for any sort of required insurance. They all want somebody else to pay for it.

Then I said: "Why did the political leadership do it?"

And he said, very simply: "We believe the success of Japan is the future of our work force, young people, and we invest in it. We cannot imagine not making basic health services available to our work force."

The moral issue is why we would compete with a work force where kids can't read and run around with unfixed heart murmurs. If that ain't a moral issue, I don't know what is. But we are the only one. The South Koreans will say exactly the same thing to you. "We don't want our work force not to get basic care. It won't work right."

We're basically spending the future capital of this country by not providing the work force, particularly young people, with adequate health care. And that a small businessman, who's worried about tomorrow's profit margin, can't see.

Chairman ROCKEFELLER. I agree with you, and that's precisely the point. It is precisely the point. We're looking at the short term.

How does the small businessperson, or indeed the larger—because they are now beginning to back away from this also, from health care costs—what are they going to do about next quarter, next year, the next 3 or 4 years? And the moral answer, you're indicating, the ethical answer or the wise answer is: "Hey, we're going to be nowhere in 5 years or 10 years unless we do this."

Mr. BLENDON. And we're going to have a work force that can't read and kids with every physical and mental disability that we can come up with. And no question, next quarter will look better, but somebody is going to be worried about the work force in the year 2000 in this country. And we're basically taking away from workers who could hear the people with their kids in problem and families in problem. Many of them are remediable problems. They're going to be there for 20 years and we're not investing in them.

Chairman ROCKEFELLER. When did Japan make that decision?

Mr. BLENDON. In 1963. I won't want to say—everybody likes to say they came up to be a big competitor, did it at once. The most interesting are the South Koreans. They made the decision in 1978. And so as not to wipe every small business out, they did it over 10 years. Start with the big ones, then keep going down. Each year it goes down one size. So the really small ones had 9 years to figure out a way to deal with this thing.

But basically, they did it. They kept it through. It's working. Honestly, the small businesses are not moving to Taiwan. I mean, this thing is going on and they say, absolutely, they couldn't run a country without doing that.

And by the way, I can't let this off the record because I'm a historian here. In 1976, the U.S. Chamber of Commerce supported Senator Fannon of Arizona's bill, which was a mandated insurance bill. It came before this committee and they testified that mandated insurance was the way this country should go. Now something's been in the water supply of this country the last 10 years and everybody has amnesia. But I would like to just leave in the record that even the Chamber reached the conclusion about this in 1976 and then reworked it somewhere in between.

Chairman ROCKEFELLER. You're both terrific, and you've both run out of time. I really thank you. This is always embarrassing in this process when people who come from a long distance have to make such a short appearance and don't get to say very much. But you both understand the process. You understand that there's a—that we are seriously at work and we're going to do something about this.

I thank you enormously for coming.

Dr. Estes. Thank you.

Chairman Rockefeller. Our final witness is Deborah Steelman, for whom I have a very high regard, who is the Chairman of the Social Security Advisory Council, and a very close advisor to the President of the United States on health matters, and obviously in this instance also to Secretary Sullivan.

We welcome you.

STATEMENT OF DEBORAH STEELMAN, CHAIRMAN, QUADRENNIAL ADVISORY COUNCIL ON SOCIAL SECURITY

Ms. Steelman. Thank you, Senator. I will be very brief.

I very much appreciate the opportunity to speak before the council. It's an honor to be a part of the Pepper Commission's important work. I won't try to add to the many levels of information you've been given this morning from the experts, from the administration, and most importantly from those people who's courage and love is so much in evidence.

There is no question that this country has to address this problem. Let me simply talk about the Advisory Council for a minute, and then talk about just one analogy to what I see as the real problem.

The Advisory Council is set up by statute, section 706 of the Social Security Act, and is appointed every 4 years. It has 13 members of tremendous expertise. The composition of the Council is, by law, balanced. A Council has been appointed every 4 years, since the mid-1930's. And as the Social Security Act broadened its authority, it now includes 20 titles, the jurisdiction of the Advisory Council was broadened as well.

We have a great, great group of people on this Council. I am very honored that they've agreed to serve. We are geographically balanced. We are balanced by constituency. We're balanced by philosophy. We're balanced by political party. We are balanced by generation. And we all bring to the task a real resolve to reach some agreement to try to cut through the partisan politics as well as the constituency politics that have precluded action on this really tragic issue for decades.

We have a split charter. Our health care charter from Secretary Sullivan is to review the funding and coverage under Medicaid and Medicare, to assess whether those programs can meet the needs of the people for the next 5 to 50 years, and if not to make recommendations accordingly. Obviously, one cannot look at those two programs, which are about $140 billion, without looking at their impact on the rest of the health care finance system, so we have broadened our jurisdiction accordingly.

We started that work in August at our first meeting, which went very successfully, and we hope to produce an interim report by July 1990. Although we're not required by statute to report prior to

January 1, 1991, we feel this issue is of premiere importance, and hope to expedite our work on it. We have been urged by Dr. Sullivan to do so.

All of our meetings are open to the public. All of our draft documents will be open to the public. We have a tremendous outreach effort underway to bring in all sorts of constituencies and expertise, so that we hope that our report will not be one big ballyhoo in July, but that we can add our expertise and staff and resources to the process as you finish your work and add any counsel the administration might require of us.

Our charter also directs us to consider issues related to Social Security retirement benefits. We're going to start that on December 7 at that meeting, and hopefully finish by December 1990.

I would like to emphasize that we are an independent council. While I have been blessed in my short tenure in Washington to advise many great politicians in this city, I am not exclusively an advisor to the administration or to anyone else. None of us are running for office and none of us are advising any particular set of political interests.

So we hope that we can take on some of the more controversial issues that have proved the roadblock to making many changes that we all, I think, in private acknowledge need to be made. Hopefully we can deal with those issues in public and take on some of the more controversial elements.

Let me just quickly say, I view health care finance in this country as a house of cards. You can either add cards at the bottom: Medicaid expense, Medicaid expansions. You can add cards at the top: Medicare catastrophic. It is still a house of cards. A house of cards can stand in a quiet room, but it cannot stand when there is wind. And we're looking at a lot of wind.

We have the wind of unmet need, which was so eloquently stated earlier this morning.

We have the wind of public dissatisfaction, which comes through in poll after poll after poll.

We have the wind of demographic change, the likes of which this country has never seen, in our aging population, in our poverty population, in our family makeup, in our work patterns, in our work locations.

And we have the wind of cost which has been blowing over the last 25 years fairly steadily and predictably, 15-percent, 20-percent, 25-percent increases.

The winds of the future cannot be ignored. At some point, there will be an economic downturn or an economic crisis that will affect our general tax base, our payroll tax base, and our employment, where many people get their insurance in this country.

This house of cards cannot stand in this wind. I too have felt a rage building in this country, but I have yet to see it exposed in any political process. If there is such rage, generally it exposes itself, witness catastrophic. That is a rage you're feeling.

Where else do you feel this rage? How many colleagues do you have who will sit through this whole meeting? How many meetings can you get with the President of the United States to discuss health care? How many times is the Finance Committee or the Ways and Means Committee, who've been the very participants who have created this house of cards, well intended as every step was, willing to sit down and say: "This is a house of cards. Let's deal with this in a comprehensive way. Let's not rush to judgment. Let's not keep filling niches," to quote you of 10 minutes ago: "let's look at this wholistically."

But I think it can be done.

[The prepared statement of Ms. Steelman follows:]

STATEMENT OF DEBORAH STEELMAN
CHAIRMAN OF THE QUADRENNIAL ADVISORY COUNCIL
ON SOCIAL SECURITY
BEFORE THE PEPPER COMMISSION
SEPTEMBER 21, 1989

Mr. Chairman, I am Deborah Steelman and I Chair the Quadrennial Advisory Council on Social Security. As you know, the Social Security Act requires that an Advisory Council be appointed every four years to review the programs authorized by the Act. The Social Security Act specifies that each Quadrennial Advisory Council is to review: the status of trust funds for the Social Security cash benefit programs, as well as the Medicare program; and the scope of coverage, adequacy of benefits and all other aspects of these programs, including their impact on public assistance programs under the Social Security Act.

This year, Secretary Sullivan asked the Council to focus its efforts in two important areas: 1) the adequacy of the Medicare and Medicaid programs to meet the health and long term care needs of all our citizens; and 2) the issues surrounding the OASDI Trust Fund surplus and the future demands on the Social Security cash benefit programs as a part of overall retirement policy. Today I will concentrate my comments on the first area, since it corresponds to the important work of the Pepper Commission. But before I discuss our substantive work, let me give you some general information about the Council.

THE ADVISORY COUNCIL

Since 1937, advisory councils have been assembled to provide expert advice to policymakers on Social Security Act programs. As in the past, the current Council is made up of a cross-section of experts and interested citizens. The members of the Council bring not only expertise but their sincere commitment to carefully examine our health and Social Security programs and to recommend ways to ensure their continued viability.

The Council is bipartisan, geographically diverse, and it represents Americans of different generations. Council members represent employees and employers, health care providers and suppliers, academic experts and the public. The Council includes several former government officials whose previous responsibilities involved managing our national employee benefit, health and retirement programs and advising legislators about these programs. These individuals thus bring direct operational and policy expertise to us. For your information, I have appended to my testimony a list of Council members.

The Council has scheduled 10 meetings in 1989 and 1990, and is charged with completing a final report to the Secretary of Health and Human Services by January 1, 1991. All our meetings will be open to the public, and we will seek wide public comment on our work throughout the process, particularly through circulation of draft recommendations for review. We owe great thanks to your willingness to make available to us the transcripts and information gathered by the Pepper Commission; because of this, we have been able to move forward quickly on the difficult issues we have been assigned. We hope our work can benefit the Pepper Commission as well.

Our staff is directed by Deborah Chollet, an expert in private health and retirement income programs who holds a Ph.D. in economics. She has recruited an excellent staff with many years of expertise in health financing and Social Security issues to serve the Council. Many of our staff are on loan to us from the Health Care Financing Administration and the Social Security Administration and we expect to draw on those agencies for technical information and support. Additional research support, including data and analysis, is being provided under a HCFA contract with Project Hope, a Washington-based group with a distinguished staff and reputation. Our staff has met informally with the staff of your Commission and we hope to continue a collegial working relationship with close staff cooperation.

We began our intensive review of health care issues in September, and our current plans call for a release date for the final draft health report of July, 1990. We will begin our work on Social Security and retirement issues beginning in December, and plan to release a final draft report by December 1990. Both drafts will be revised and included in the final report to the Secretary of Health and Human Services. As specified in the Social Security Act, the report is then transmitted to the Congress and to the Board of Trustees of the Old-Age, Survivors, Disability and Health Insurance programs.

HEALTH CARE FINANCING REFORM

You have asked me to address the problems of health care finance today. You have already heard from several persons more expert than myself. Secretary Sullivan has described many of the inadequacies of our financing system -- millions of people without coverage, the complexity of our public programs, the inferior reach of Medicaid to help our poor, the lower health status of our minority citizens, the immense cost of our system while producing results that compare poorly with other nations' smaller investments.

More importantly, you have heard from the true experts themselves, the people who have groped without success for decent health care coverage, something that is truly unthinkable -- unbelievable -- in a nation of our wealth and compassion. I can add little to their testimony.

Let me simply describe the problem this way: the government and the private sector interact, overlap, duplicate and omit financing for many services and people who need health care today. This has been caused by the meandering path of health care finance this nation has wandered down for the last 100 years. It grows more complicated and less satisfactory every day. Many of you have watched this happen during your long years in Congress; you have struggled to put common sense into these laws. But health care is not an issue your peers on either end of Pennsylvania Avenue have taken very seriously. And so you fought for an inch or two when you knew you needed ten thousand miles.

Instead of the compassionate and cost-effective system we wanted, we have created a disfunctioning health care market filled with great inequities and cost escalation, where the public/private partnership is instead a public/private cost-shift war. And in the process of fighting this war, we have invested many constituencies -- providers, financers, beneficiaries -- in the status quo, to the virtual defiance of personal and societal goals and needs.

The magnitude of this disfunction presents both the opportunity and the need to think beyond our current programs and policies -- to consider systemic reform. I personally do not believe that marginal change can solve problems of access, quality, and cost in American health care in any meaningful way. I believe that most of the Council members share this conviction. Thus we are committed to think broadly, to investigate significant and fundamental change, and to focus on both the current and future needs of our citizens as beneficiaries and taxpayers.

At the Council's first meeting, we examined the demographics that will radically alter the numbers and mix of citizens who will need health care and income security support in the future. We also reviewed current Federal programs and discussed their accomplishments and shortcomings. We noted that systems that have worked reasonably well in the past may require significant change if we are to meet the challenge posed by the Nation's growing health and long-term care needs when the baby boom enters retirement early in the next century. We discussed the principles that we believe should be present in the American health care system, and drafted a statement of principles. We are circulating this draft widely and requesting comment from any interested parties. I would like to share it with you today:

All people should be able to obtain necessary health care. All citizens share the cost of health care; these costs should be distributed fairly and consistently with the nation's long term well-being. Individuals, employers, and government should have a role in paying for health care. Methods of health care delivery and financing should constrain growth in health care expenditures commensurate with improvements in the value of health care. Health care services should provide the most effective treatment in the most cost-efficient and compassionate way.

The Council is committed to recommendations that act boldly on these principles. In coming months, we will consider various proposals addressing the features of our health care system that are inconsistent with these principles. We will consider systemic restructuring as well as replacement of existing programs. We will consider new programs and policies that promise greater success in closing the many gaps in access and financing we have now, and ensuring a continuum of needed health and medical care services for preventive, acute, chronic, and long term care. Every option -- no matter how different, no matter how unconventional -- will be considered. We will try to stretch the ways we have all come to think about health care financing and delivery in this country.

SOCIAL SECURITY AND RETIREMENT INCOME

In his charter to the Advisory Council, Secretary Sullivan asked the Council to also focus on the relationship of trust fund income and outgo to Gramm/Rudman/Hollings deficit reduction targets; the projected buildup of significant trust fund surpluses; and broad policy issues, such as the role of Social Security in overall retirement income policy. Such issues include the future of private pension plan coverage, the role of personal saving, trends toward early retirement and the role of means-tested assistance programs for the elderly.

In their last report to Congress, the Trustees of the Old-Age, Survivors and Disability Insurance Trust Funds asked the Advisory Council to convene a panel of experts (including actuaries, economists and demographers) to advise the Council on the measures that should be used to judge the program's short-range and long-range financial soundness. While these issues are quite technical, the answers are critical to the programs and to the American people. The answers guide their thinking and underlie decisions about the viability of the cash benefit system that so many count on, both now and in the future.

At our meeting on December 7-8, 1989, the Council will begin its consideration of issues relating to Social Security's retirement and income security programs. We will distribute a draft of our recommendations on these programs for review and comment the following December.

CONCLUSION

This nation has a window of opportunity to examine alternatives and develop major reform strategies, particularly for the way we finance health care. This window will narrow as health care costs continue to rise out of control and as the needs of an aging population force crisis decisions, even in the next decade.

We of the Advisory Council believe our job is to push ourselves to see and understand the health care and income security implications of the next five to fifty years, and to devise the new thinking, and new approaches that the future demands. We demand from ourselves creativity, imagination and vision. I believe that this is our opportunity and our duty.

I would be delighted to answer any questions you or members of the Commission may have, Mr. Chairman.

Chairman Rockefeller. Do you think—I'm sorry to interrupt. Did you think the reason that we're not reacting is either of the following two: One, that we haven't really understood the dimension of the anger and of the problem until recently, at least most of us have not; and/or second, that those whose interest it is to see this system not change or at least not change to their detriment are in effect blocking and discouraging Congress, from taking action?

Ms. Steelman. A couple of things:

No. 1, health care finance is the most complicated and intractable public problem I've ever dealt with, and I've had some generic experience in several fields, in environment, education, taxes. Health care finance is extremely difficult. The interests, even at the consumer level, are extremely diverse.

As a member of the Finance Committee, I'm sure you've experienced the fact that it's much easier to go into a room and talk about how you've lowered someone's taxes, or to go into a room and talk about how you've really beat the Japanese this time. It is very difficult to go into a room and say: "Here's what we're going to do on health care." That's why I applaud very much your leadership on this issue. You're willing to spend the time on a tough issue for which there is currently little political percentage. That's point 1.

Point 2, it is not that you haven't understood the depth of the problem. I think, as witnessed this morning, many of us have heard and are very familiar with the problems in health care finance. As Congressman Gradison said earlier, it's not that we don't understand the problems, it's that we haven't buckled down to figure out how to finance it.

Well, there are reasons for that. There is no political constituency out there that is forcing it to the agenda. We have a serious problem in poor people's health care in this country. It's immoral. We have a Medicaid system that is not second tier, but fifth or seventh tier. But how many of your colleagues, if given 5 minutes to talk to the President of the United States, would say: "We've got to fix poor people's health care in this country."

Eighty percent of the country has some kind of health care coverage, and know that the trend is toward dissatisfaction. But the Employee Benefits Research Institute study of only 2 weeks ago, indicated that 80 percent of the people who have private health insurance are relatively satisfied. This is not the basis from which political rage is built.

However, we must face the winds of change that I and others have mentioned here today, the unmet needs, the poor people, the people who's economic future is threatened by our lack of investment in them, and make public policy accordingly. That's why your work, the bipartisan work of the Pepper Commission, the Advisory Council's bipartisan work, people who can look a little further forward and say: "We have to figure out a way to quit stacking cards on this house, to take real 2 by 4's and real nails. To do something that works. If we have to throw out something that this Committee has invested in for the last 20 years, well let's face up to that."

Does that answer your question?

Chairman Rockefeller. That sounds fair enough.

The instinct—see, the other side you've mentioned, the 80 percent that do have private insurance, are basically satisfied with it. But then you get back to that 11 percent poll figure, and assume it's off by 3 to 5 percent either way, that's a basic sense that either something is about to be very wrong or something is very wrong in terms of health care in this country for approximately 90 percent of the people. So where does the 80 percent who are satisfied, the 90 percent who are saying no—how does that work?

Ms. STEELMAN. Well, I have had enough experience with surveys to know that that's not what public policy should be based on. There are various ways you can ask survey questions to get to various results. Most of the political polls with which I am familiar—both polls that have been taken for Democrats running for office, polls that have been taken for Republicans running for office, polls that try to figure out where am I going to get that 51 percent of my vote that's going to get me elected—health care does not show up in the top five or six or seven issues.

Chairman ROCKEFELLER. That's true.

Ms. STEELMAN. And that's why you're sitting here alone. But thank goodness, you're sitting here. And your role in this and that of your colleagues is critical. Public policy demands that we start investing our time and that we apply ourselves in new and creative ways.

For example, I talked about building a house with 2 by 4's and nails. There are a lot of people who think the only house that can be built is national health insurance. I personally—and I'm speaking personally, not for the Council—believe that fantasy has kept us from doing many of the things we need to do over the last 50 years in health care finance. There are many reasons, unique and of long standing in the American culture and the American political system, that a monolithic national health insurance program hasn't happened.

I think that there is still—and some could say catastrophic has proved this—a belief that some people would rather pay premiums than taxes, as illogical as that may sound. We are going to have private sector involvement in health care. We're going to have significant public sector involvement in health care. There's going to be Government, employers, and people involved in the financing of health care, all of which of course flows from the people.

These are real elements. I have my feet on the ground. Just because I say systemic reform is necessary does not mean that I am not a pragmatist. I also believe systemic reform is possible. I really think it's possible. I think you could make the public sector interact under Government rules, and the private sector interact under Government rules, and have both sectors work together.

I don't think there's a need, for example, in Medicare, to have one payer in part A, one payer part B, one payer to catastrophic drug proposal, one payer in Medigap, one payer in Medicaid, and a little bit out of my private pocket. This makes no sense. I think we can change these things, because of you.

Chairman ROCKEFELLER. Well, incidentally, I'll defend at least some of my colleagues on this Commission. Two of them had to chair hearings. One of them was on toxic wastes which has something to do with health, so that person is excused. And I agree with you about the absence of some of the others.

Ms. STEELMAN. No, please let me say I'm not criticizing the members of this Commission.

Chairman ROCKEFELLER. No, but I am.

Ms. STEELMAN. I'm not.

Chairman ROCKEFELLER. I am.

Ms. STEELMAN. Because everybody has important business.

Chairman ROCKEFELLER. I am, and they're going to get letters.

The rush to judgment suggests, or the sort of negative connotation about rush to judgment, suggests that there are as you indicate pieces that could be put together, public and private, that can work.

What becomes so difficult is two things: One, even beginning to understand the system, the health care system, is the province of so few intellectually, in terms of knowledge. Let's say, within the Congress, maybe there are 20 at the most in the Congress in both bodies who understand health care.

Ms. STEELMAN. That's true at the other end of Pennsylvania Avenue as well.

Chairman ROCKEFELLER. And I would suggest the same. So that's a problem, getting people to understand what the problem is, even as the problem is crashing over the tops of us.

I mean, in the so-called Gorbachev Window, it's interesting to me in the last 1½ years the national defense budget hasn't been really the subject of many articles. There's not that much discussion about it. Of course, it's very intense, but other things have really come up very rapidly. Children, for example, I would suggest have come up extremely rapidly. There is no constituency group for children at all, or any national policy at all for children, not even bits and pieces.

So the problem, one, is the knowledge, getting the knowledge. You can't act until you have the knowledge. But on the other hand, you can't move time forward 10 years until everybody has the knowledge, because many of them wouldn't seek it even if they had 10 years.

Everybody is saying we've got to do it now, and I agree with that. So that means, then, that there does have to be a stitching together if one does not go toward national health insurance or let's say the Canadian or the British plan.

There has to be a stitching together, and it is so incredibly difficult. Because, one: How do you do the stitching so that you mix private and public and personal? And then second, how do you get the institutions involved in all of that to agree to cooperate in any way, shape, or form with whatever you come up with?

Now I think you covered yourself at the end there by suggesting it should be federally directed. Am I right, that this process should be federally directed, not federally led but federally stitched?

Ms. STEELMAN. I think there's no other choice. The fact of the matter is much of what we have in health care today is defined by the Federal Government, sometimes by omission, sometimes by commission.

The reason we have certain markets today is because of the Federal Government's definitions. The Federal Government has usurped the whole province of acute care needs in Medicare, which means the only product that is left to sell is long-term care and Medigap. Your precise words are quite accurate: "filling niches."

Is there a way that the Federal Government could define a more useful purpose for the private market? I think there probably is.

Chairman ROCKEFELLER. Well, we've got to stop. You have written me a very interesting communication in which you say that you would like to cooperate with us. I want to do that.

I really do have this feeling that—I'm not making a prediction, but I think catastrophic health care is in real trouble. The bill is in real trouble in the Congress. And I am simply stunned by that fact. I'm not on the surface, because if $800 supplemental for every living person over 65 is the perception, then the perception always wins out over the reality. I mean, that argument is fairly clear.

President Reagan said it has to be self-financed, and therefore it was passed on the self-financed basis.

And people say: "Well, you can't do that. You've never done this before. You say that we have to pay for it all by ourselves."

And then others would come back and say: "Yes, but look. Times are rather different and everything is going to change, including lots of things that will be painful."

I really do think that your Quad Commission and our Commission here on comprehensive health care have extraordinary possibilities to make enormous contributions in a very short period of time. Because, across your Commission is an enormous amount of expertise in the membership, as is the case with ours, six Senators, six Congressmen, minus expertise in this Chairman, and a superb staff, and a mandate with Claude Pepper watching. I mean, that's a lot of motivation.

I really do think that the Nation has a right to turn to us, perhaps primarily, or perhaps equally with you to stand back and answer these questions on access, on quality, on cost, fearlessly, ruthlessly if that has to be the word, because systems will be changed and lives will be made less comfortable. But I really do think we have to do it.

And having said that, Debbie, I thank you for being here.

And I would adjourn this hearing by saying that our next public meeting will be on October 5.

Ms. STEELMAN. Thank you, Senator.

Chairman ROCKEFELLER. Thank you.

[Whereupon, at 1:27 p.m., the hearing was adjourned.]

APPENDIX

NMF NationalMarfanFoundation

382 Main Street, Port Washington, New York 11050
516-883-8712

Dave Cowens, Honorary Chair
Reed E. Pyeritz, M.D., Ph.D., Professional Advisory Board Chair
Priscilla Ciccariello, NMF Chair

TESTIMONY FOR THE U.S. BIPARTISAN COMMISSION ON COMPREHENSIVE HEALTH CARE--THE PEPPER COMMISSION

Mr. Rockefeller, members of the United States Bipartisan Commission on Comprehensive Health Care, the Pepper Commission, I thank you for the opportunity to present testimony on behalf of the 30,000 Americans afflicted with Marfan syndrome and an additional 500,000 affected by other Heritable Disorders of Connective Tissue.

I am Priscilla Ciccariello, Chair of the National Marfan Foundation, the Coalition for Heritable Disorders of Connective Tissue, and a member of the Board of Directors of the National Organization for Rare Disorders. The primary focus of this testimony is on behalf of the constituents of the National Marfan Foundation (NMF), a small non profit national health agency providing programs and services for patients and families with Marfan syndrome.

Marfan syndrome is a progressive, incurable, and potentially fatal genetic disorder of the connective tissue characterized by tall stature, long limbs and fingers (some medical historians have suggested that Abraham Lincoln may have suffered from Marfan), scoliosis, cardiac complications (the most common is aortic aneurysm), and subluxation of the lenses of the eyes. An estimated 30,000 people in the United States have this condition, but for a number of reasons many do not know they have it.

Affiliations
National Organization of Rare Disorders, Alliance of Genetic Support Groups,
National Voluntary Health Agencies, Coalition of Heritable Disorders of Connective Tissue

This leads me to two specific concerns of the Foundation in regard to the Pepper Commission's work:

(1) The lack of knowledge about Marfan syndrome in the public and in the medical profession which hinders diagnosis and treatment and unjustly denies affected persons Social Security Disability Insurance, other entitlements, and private health care insurance.

(2) The rising cost, growing cancellations, and general unavailability of private disability and health insurance for people with Marfan syndrome.

First, the lack of knowledge about Marfan syndrome. I have spoken to physicians, many of whom have said they heard only two to three minutes on Marfan in medical school, or only heard about it named in one lecture on connective tissue disorders. With this little focus, the misdiagnoses, or missed diagnosis are much more understandable. Many people with Marfan syndrome go years without diagnosis. All too often, this can lead to severe handicapping conditions and/or unnecessary death.

One such person was Flo Hyman, the Olympic volleyball player who died in January of 1986 of a ruptured aortic aneurysm associated with Marfan syndrome. I met Flo's sister at the National Marfan Foundation Conference in August 1986. She told all of us how Flo had gone undiagnosed all those prior years even though she had numerous physical exams. Flo's sister went on to tell us that the family was never informed that Marfan was an inherited condition - even after Flo's death. It was only after a medical writer covering the story told her there could be a fifty-fifty chance of other family members having it that her brother was diagnosed and was found to have an aorta close to rupturing. He did have subsequent successful surgery.

My own son was diagnosed at autopsy (age 22) and my husband died at age 59 from complications of Marfan syndrome. Two of my other sons and several of my grandchildren are also affected. Those of us in the NMF hear these stories of tragedy time and time again. Sadly, these stories repeat themselves for millions of Americans affected by more than 5,000 known rare disorders. The report of the National Commission on Orphan Diseases, recently submitted to Congress, found that more than 50% of patients with rare diseases went more than five years (some more than 10 years) without a diagnosis of their disorder.

In cases where Marfan syndrome does not cause death, it can have severe disabling effects. During the seven year existence of the National Marfan Foundation the severe debilitating and life threatening nature of Marfan syndrome has been well documented. There are 10,000 on our mailing list who bear evidence to this fact. Recently we have had numerous calls and letters from families asking us to intervene on their behalf with the Social Security Administration and with private insurance companies because they have been denied disability and medical coverage.

Medical reporting lags behind the reality of the many manifestations of the Marfan syndrome. It is only in the last few years that any attention has been directed to this disorder. Currently there is only one therapy, the use of beta blockers, to attempt to control degeneration of the cardiovascular system. There is also severe muscular and skeletal weakness and degeneration which have no effective treatment at this time. Therefore, the Marfan syndrome often results in disabling handicaps including blindness.

The National Marfan Foundation is currently working with the Social Security Administration to modify current criteria to incorporate the debilitating aspects of Marfan syndrome in the "Listing of Impairments". This listing is organized by category and at present does not recognize the Marfan syndrome as a multiple systems disability; yet, the comprehensive, progressive involvement of this disorder should place it in this category of disabling conditions.

The problem with the Social Security Listing of Impairments has far reaching effects in the private sector. Because many insurance companies refer to this listing when making their eligibility determinations, people with Marfan syndrome are often denied coverage because the companies do not find it among the conditions listed by SSI.

In the last two years the number of letters we have received from families regarding denial, cancellation, and unavailability of health insurance coverage has grown increased at a rapid rate. Many write to ask which states have high risk pools so that they might move there; others tell us that they cannot even get insurance in some of those states which have passed legislation for these types of pools. Several letters typifying the insurance problems of a growing number of families with Marfan syndrome accompany this testimony.

In addition to the problems of patients now without adequate insurance, we at the NMF are very concerned about our children with Marfan syndrome. Even if they are fortunate enough to be covered by their parents' insurance policies, when they become of age, they will be uninsurable because of the preexisting nature of the condition. What will happen to them?

Without adequate health insurance coverage for long term care, Americans stricken with Marfan syndrome and other rare genetic disorders have little hope for survival. I refer not only to basic survival, but to a quality of life that enables families to survive together. The toll taken by these illnesses is enormous, both financially and emotionally. Families can be devastated since multiple family members are often affected. In many cases the wage earner dies leaving the partner with several children in need on ongoing medical care and treatment. Drug therapies, the only treatment now known, can cost several thousand dollars per year, life long. Additionally, the open heart surgery, needed in many cases, costs thousands of dollars. All too often these families are refused medical insurance and become financially as well as emotionally devastated.

This tragedy is repeated in tens of thousands of families affected by Marfan syndrome and the thousands of other genetic rare disorders that receive little attention.

As the spokesperson for people with Marfan syndrome and other heritable disorders of connective tissue, I urge this committee to find ways in which this country can provide care and insurance for all who need it. When patients affected with Marfan syndrome and other heritable disorders of connective tissue are diagnosed and treated properly the great majority can be and are productive, tax paying citizens with many positive attributes. These people, their families and their future generations deserve the opportunity to contribute to our society rather than to be devastated by it.

531 Marian
Lima, Ohio 4580
Sep 11, 1989

Dear Chairperson,

My husband Jack is a victim of Marfan's Syndrome. He just turned 47 years old on Sep 6, 89.

Among the complications of Marfan which have plagued Mr. Risner are severe visual impairment with corneal transplants and retinal detachment; acute hearing loss; and aortic regurgitation with mitral valve prolapse which flailed in March of 89 sending Mr. Risner into Congestive Failure. Emergency surgery saved his life and he is now functioning well with two St. Judes Valves.

Although we have received the Connective Issues for quite some time, I have never set aside the monies to become a member of your Foundation. Money is quite scarce at this time, but perhaps in the weeks to come the money will become available to pay a membership fee.

In the meantime may I be so bold as to ask for your help?

Last June, Mr Risner changed his place of employment. Being naive to the complexity of the Blue Cross System we assumed that his hospitalization coverage would transfer from B.C. Northwestern, to BC Community Mutual. without any pre-existing problems. His new coverage was effective August 1, 1988.

We experienced no problems for the surgery for retina repair in December of 88, even though it is a complication of Marfans. The problems began in March of 89 when Blue Cross Community Mutual refused to pay his Open Heart expenses because of pre-existing reasons, even though the flailing of a valve is also a complication of a Marfan's Syndrome

Mr. Risner had his yearly Echo-cardiogram in January 89 which showed no change from the previous year. His problem could not be considered pre-existing.

I have appealed to Community Mutual and will soon be filing a complaint through the Ohio Insurance Commission. I have writte letters to Senator Robert Cupp, Ohio, Congressman William Thompson, Ohio; Ohio State Senator Michael Oxley and Congressman Marc Guthrie who just introduced a bill into the Ohio legislature for pre-existing insurance coverage. I am getting nowhere! We owe over $50,000 in medical bills.

I have been advised to file bankruptcy but this is contrary to my convictions. Our creditors of late, have been turning their bills over to collection agencies.

Would you be so kind as to point me in the right direction to get help on this matter?

I am providing these addresses to assist you should you decide to intervene for us in this matter.

Community Mutual
Blue Cross, Blue Shield
P.O. Box 425
Worthington, Ohio 43085

Representative Marc Guthrie
State House
Columbus, Ohio 43216

Sincerely..

269 Red Clay Rd. #302
Laurel, MD 20707
August 10, 1989

Ms. Priscilla Ciccariello
Chairperson
National Marfan Foundation
382 Main Street
Port Washington, NY 11050

Dear Ms. Ciccariello,

My husband, Rich, has Marfan syndrome. He was diagnosed almost two years ago just before he had surgery to replace his aortic valve and aortic root. He is in stable condition and participates in a study at Johns Hopkins Hospital in Baltimore. We have two babies under three being followed by Hopkins although neither has been diagnosed with Marfan.

I am writing for two reasons. The first is that Rich is still very much in denial. He doesn't want to talk about Marfan and doesn't want to know anyone with it. On the other hand, I wish I had someone to talk to about it. I don't know of any support groups in Maryland; Hopkins wasn't too helpful in that area. I wonder if there is such a group in Maryland?

The second reason I am writing is that Rich's company raised health insurance rates again (100% in two years) and we can no longer afford the family plan. As you are aware, by dropping the children, we are risking large bills. I called Mr. Fried at the National Health Care Campaign because I want to help change the health care system, and he suggested I write to get on the newsletter list. I would like to receive the newsletter very much but we can't afford it. We were in bankruptcy by last summer--even with the crummy insurance we did have at the time, and we are still weighed down by huge bills. May we get on the newsletter mailing list and then when we have the money, pay the dues?

Thank you for your help. I am planning to **fight** as hard as I can for affordable health insurance. I will not let my family go down the drain without a fight.

Sincerely,

P.S. I do have an HMO so at least we are not totally without protection. However, too many are!!

July 20, 1989

National Marfan Foundation
382 Main St.
Port Washington, N. Y. 11050

Please Help. I have just been notified the Florida is cancelling their state health insurance. I will have to move to another state that offers such a policy for us losers.

Do you have a list of the states offering a policy to people who can't get insurance from any regular company.

I do know that New Mexico just passed such a law but I don't know how many other states have it

Thanking you in advance for your help

Jacksonville, Fl. 32223

Statement for the Record

for the

Pepper Commission

United States BiPartisan Commission on Comprehensive Health Care

August 30, 1989

by

Belen B. Hickman, Director
Mobility Services, Inc.
Atlanta, Georgia

on

The Need for Coverage of Orientation and Mobility Services for the Blind under Medicare

For further information contact:
Ms. Belen Hickman
MSI, Inc.
761 Peachtree Street, N.E., Suite 3
Atlanta, GA 30308
404-876-2636

Glenn M. Plunkett
American Foundation for the Blind
1615 M Street, N.W., Suite 250
Washington, DC 20036
202-457-1496

Statement for the United States BiPartisan Commission on Health Care

This statement is submitted for the record in hearings concerning comprehensive health care in the United States. This statement is submitted on behalf of the Orientation and Mobility Interest Division (#9) of the Association for the Education and Rehabilitation of the Blind and Visually Impaired (AER) and the American Foundation for the Blind (AFB).

AER is the only individual membership organization dedicated to the advancement of education of blind children and adults, and promotes all phases education and work for the blind. AER is the certifying body for O & M specialists and rehabilitation teachers. Division 9 is the certifying group in AER for O & M specialists.

The American Foundation for the Blind is a national nonprofit organization whose primary mission is to ensure the development, maintenance and constant improvement of services for blind and visually impaired people in the United States.

On behalf of myself, the organizations mentioned and all people who meet the definition of blindness, we ask that the Commission recommend to the Congress that orientation and mobility services for blind people be covered under Medicare or as part of whatever health system is established as a result of your work.

Blindness is defined as in the Social Security Act (20 over 200 or less in the better eye with correcting lenses , or peripheral vision of 20% or less in the better eye). Orientation and mobility is the course of instruction (therapies) used to develop safe, efficient and effective travel in any environment with use of the long cane which gives a blind person the capability of being a participating member of her community. Providing a blind person orientation and mobility techniques permits the individual to move about his home independently and with confidence. The O & M specialist teaches the blind person to recognize dangerous situations, use remaining senses, including residual vision, and to get to destinations safely and effectively using way finding techniques. The individual is taught to independently travel on sidewalks, in crossing streets and in using mass transit.

For those who are employable,effective mobility skills are necessary for employment and for the elderly are instrumental in preventing premature entry into a care situation such as a nursing home. With O&M and with the proper use of rehabilitative services, blind people can function effectively in the home and in the community. The achievement of independent living skills with the techniques that could be available to the elderly blind, more costly services can be avoided. It is widely estimated that nursing homes cost from $25,000 to $35,000 per year. The offsets to be gained by providing O&M skills (approximately $800 per person) and other useful devices (such as low vision aids which should be covered by Medicare) to avert the more costly care situations is not only cost effective but restores an active member to society.

In the case of younger persons who lose their sight, if they meet the Social Security criteria for benefits, they are referred to the state rehabilitation services for rehabilitation if they have vocational potential. But, they are not covered for such services under Medicare even after they have been on the Social Security disability rolls for two years.

Currently almost 4,800 people are found annually to be disabled for Social Security disability purposes and are automatically referred for Vocational Rehabilitation (Social Security Data provided to the American Foundation for the Blind, April 11, 1988). However, for those blind people who do not have a vocational potential, and the blind elderly who seldom have an opportunity to participate in vocational programs the only recourse is purchase of the services.

For veterans who are blinded (including those who became blind as they age), services such as O & M are provided by the Blind Rehabilitation Services under the Department of Veterans Affairs Health delivery system. Information from the Blinded Veterans Association indicates about 800 veterans are given such services each year. The numbers are growing because of the aging of veterans from World War II and later conflicts.

The numbers of blind individuals increase as the numbers of individuals living past age 65 grow larger. As the elderly population grows older, the incidence of blindness increases even though the individuals may be in relatively good health otherwise, yet the blindness robs them of independence unless they are provided with the therapy to give them that independence. O&M, for the purpose of this statement, is referred to as a therapy since it is equated with other therapies such as physical therapy and occupational therapy. O&M restores the capability one has to function and travel independently as physical therapy restores the capability to use an injured limb or make use of a prosthesis.

Currently, individuals with Medicare coverage who suffer handicapping conditions such as broken bones, strokes or other problems can and do receive occupational and physical therapy services with Medicare reimbursement in an attempt to restore them to independence. However, the same person who suffers a broken leg and blindness in the same accident, or otherwise, will not be provided with orientation and mobility to restore his capability of independent travel. For example, a person who walks off a porch because of blindness and breaks a limb will receive therapy under Medicare to teach her how to use the limb again but cannot receive O&M under Medicare to teach him how to walk safely to prevent future falls.

It is expected on the basis of data from the 1977 National Center for Health Statistics that 367,000 individuals age 65 and over will be blind by the year 2000; 130,000 of them will be over age 85. By the year 2015 the number of blind persons over age 65 is expected to be 524,000. If Medicare coverage is provided for O&M services it is expected that 4,065 would be served in 1990, increasing to 8,130 in 1995 and by the year 2000 as many as 16,000 would be served. The attached data show current costs and projections.

Again, I thank you for the opportunity to point out that a segment of the population does not have health care coverage for a very important therapy that can give them independence and help restore a sense of dignity and self worth. Blind people want to participate in the community and to maintain their independence like the rest of us. Your recommendation for this coverage will help that case.

COST PROJECTIONS FOR MEDICARE COVERAGE OF O&M SERVICES

By 1990 the legally blind population over age 65 is projected to reach almost 330,000 persons; by 2015 the population is projected to reach 524,000 persons (see Appendix I). Due to limited funds for serving this aged population, it is unlikely that the number of persons over age 65 who will receive O&M services in 1990 will exceed 5,000 persons (see Appendix II). The number of aged persons served in O&M can be expected to grow in proportion to the amount of Medicare funding provided.

By 1990 it is projected that O&M services to the over age 65 population will cost approximately $810 per person (see Appendix III). The cost to Medicare would depend on the fee schedule established by the Secretary of Health and Human Services. If 80% of the fees were covered, the projected cost to Medicare would be approximately $650 per person, totalling approximately $2,640,000 in 1990.

APPENDIX I

Projections for the Over 65 Year Old Legally Blind Population in 1990 and 2015

1990	2015
329,700[a]	524,000[b]

[a] From Uslan, Mark M., Provisions of O&M Services in 1990, Journal of Visual Impairment and Blindness, May, 1983. Estimates were derived by applying the prevalence of legal blindness to the U.S. population in 1980. Sources:Vision Problems in the U.S., New York:National Society to Prevent Blindness, 1980; and U.S. Bureau of the Census, Projections of the Population of the United States: 1977 to 2050, Series P. No. 704.

[b] Calculated by the Social Research Department of the American Foundation for the Blind. Based on estimated rates of legal blindness from the National Society to Prevent Blindness and Spencer, Gregory, Projections of the Population of the U.S. by Age, Sex, and Race: 1988-2080, January, 1989 (In Current Population Reports: Population Estimates and Projections, Series P-25, No. 1018, U.S. Department of Commerce, Bureau of the Census).

M. Uslan
American Foundation for the Blind
New York, NY
July 5, 1989

APPENDIX II

Projections of the Number of Persons Over 65 Years Old who will be Served by O&M Specialists in 1990, 1995, and 2000

1990	1995	2000
4,065[a]	8,130[b]	16,260[b]

[a] From Uslan, Mark M.; Peck, Alec F.; and Kirchner, Corrine, Demand for O&M specialists in 1980, Journal of Visual Impairment and Blindness, January, 1981 and Uslan, Mark M., Provision of O&M Services in 1990, Journal of Visual Impairment and Blindness, May, 1983.

[b] Calculated by assuming that the number of over 65 year old persons served by O&M specialists would double every 5 years from 1990 to 2000.

M. Uslan
American Foundation for the Blind
New York, NY
July 5, 1989

APPENDIX III

Cost Projections for the F.T.E. O&M Positions Required to Serve the Over 65 Age Group in 1983, 1987, and 1990[a]

1983	1987	1990
$2,086,110	$2,990,250	$3,296,750

[a] Sources: Uslan, Mark M.; Peck, Alec F.; and Kirchner, Corrine, Demand for O&M Specialists in 1980, Journal of Visual Impairment and Blindness, January, 1981 and Uslan, Mark M.; Hill, Everett W.; and Peck, Alec F., The Profession of O&M in the 1980's, New York:AFB, In Press. Assumptions:

1. Base of 1480 F.T.E. positions in 1980 and growth of 54 F.T.E. positions per year from 1980.
2. Median O&M salary of $19,500 per F.T.E. position in 1982-1983. Salaries projected to 1987 by applying the yearly consumer price index through 1987. Thereafter, salary growth of 5% per year was applied.
3. The percentage of persons over age 65 on all O&M caseloads as of 1983 (24%) remains constant through 1990.
4. Since services to the over 65 age group require significantly less time to provide than services to younger persons, an across-the-board cost reduction of 50% was applied.

M. Uslan
American Foundation for the Blind
New York, NY
July 5, 1989

ALLIANCE of Genetics Support Groups

A Coalition of Voluntary Organizations and Professionals

September 20, 1989

Senator John D. Rockefeller IV
Chairman
The Pepper Commission
United States Bipartisan Committee on
Comprehensive Health Care
140 Cannon House Office Building
Washington, D.C. 20515

Dear Senator:

I send this letter to you in lieu of personal testimony for the hearing before your Committee on September 21, 1989. I write to you on behalf of the Alliance of Genetic Support Groups, which is a coalition of voluntary health organizations and genetics professionals. I am a volunteer member of the Alliance Board of Directors and its volunteer chairman of its public affairs committee. I am also the former President of the National Tuberous Sclerosis Association and the father of a child with tuberous sclerosis, a neurological genetic disorder. The Alliance of Genetic Support Groups represents the several thousand members of the more than 70 different member organizations. The Alliance is dedicated to fostering a partnership among those affected by genetic disorders and professionals in order to enhance education and service for, and represent the needs of families and individuals affected by genetic disorders.

My remarks to you will be brief and hopefully convey to you the concerns of people affected directly and indirectly by genetic diseases. We've all heard much in recent times of the progress made in genetic research. We witness with awe the Genome Project by which Congress fostered the mapping of the entire human genetic makeup. We've heard much about the exploding world of genetics and genetic research, but as we speak, the Subcommittee on Health of the Senate Appropriations Subcommittee seeks to cut research grants in genetic research from the National Institute of Neurological Disorders and Stroke of the National Institutes of Health. While I do not write you in my individual capacity, I cannot ignore the fact that one of those grants is directly related to finding the genetic linkage of causation of tuberous sclerosis and its related cousin, neurofibromatosis. My child is fortunately not severely afflicted at this point, but this research, particularly given its focus and the young age of my child, directly affects her

Thirty-eighth and R Streets, Northwest, Washington, D.C. 20057, Telephone 202-625-7853

future and the future of any children she might eventually have. In short, we seek your support for continued research. Such research is not a matter of luxury to the people that we represent. I mean no hyperbole but it is literally a matter of life or death. We believe that such research will ultimately reduce the cost of comprehensive health care and should be a part of any ultimate plan for comprehensive health care.

Recently, a survey of the individual members of our component organizations regarding comprehensive genetic services was conducted by the Alliance through the Columbia University School of Social Work. An analysis of the responses indicated that difficulties in obtaining insurance was the most predominant theme encountered. Many members reported that they or their children did not fit into clear categories of eligibility; those who had managed to obtain some sort of coverage often described long and frustrating appeal processes because of the rarity of their disorder and lack of knowledge on the part of Social Security or insurance officials. As one parent wrote: "Financial aid and medical insurance has been the biggest example of frustration we have ever been involved in." Personal and family stresses generated by the multiple costs of the illnesses also were often noted.

As our study indicates, the more important and more immediate concern of most of our members is the issue of insurance. I trust that I need not point out to the members of this Committee the extraordinary rise in medical costs generally in this country. When you put that rise in the context of a chronic and often rare disorder, even without specifics, one can imagine how the numbers related to cost increase. One soon can get an appreciation for the significance of the description of "catastrophic." I, myself, have been fortunate to date. I am relatively well off, but I know parents who have lost homes-not fortunes, but a basic place to live-because of medical expenses. They live near poverty as a result of the medical conditions of their children. I ask, indeed I implore you, to give this matter great attention. We appreciate the limitations imposed by law and the structure of government. We realize that you are but one Commission. We also realize the budgetary limitations of everyday life and the fiscal considerations involved, but we ask for our share of the pie and we hope that you will support us in this regard.

Thank you very much for your time and attention.

Sincerely,

Joseph P. Smith III

Joseph P. Smith, III
Chairman, Public Policy Committee
Alliance of Genetic Support Groups